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ABSTRACT

This document contains 12 papers presented to medical and vocational rehabilitation professionals on the topic of vocational rehabilitation and End Stage Renal Disease (ESRD) at a Denver conference in 1979. The following papers are contained in this report: "Rehabilitation and ESRD: Services with a New Thrust" by Kathleen E. Lloyd; "Medical Management of the ESRD Patient" by Alvin E. Parrish; "Hemodialysis--of Machine and Man" by Norman C. Kramer; "Adjustment to Dialysis--A Consumer Point of View" by John M. Newmann; "Peritoneal Dialysis--As a Long-Term Treatment Modality" by Michael I. Sorkin; "Transplantation--New Directions and Patient Selection" by Israel Penn; "Vocational Potential of ESRD Clients" by Helen L. Baker; "A Comparison of Long-Term and Short-Term Hemodialysis Clients" by Dorothy J. Parker; "Utilizing Work Potential--Vocational Assessment and Job Placement" by Sheldon Yuspeh and Kalisankar Mallik; "Sexual Adjustment and ESRD" by Gary T. Athelstan; "Adjustment to Transplantation--A Consumer Response" by C. Norman Weaver; and "Counseling the ESRD Patient for Vocational Planning" by Elizabeth Rose. A program evaluation and a list of workshop faculty and participants are included in the document. (KC)

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PROCEEDINGS OF THE WORKSHOP

VOCATIONAL REHABILITATION AND END STAGE RENAL DISEASE

December 11-13, 1979

Denver, Colorado

Sponsored jointly by

The George Washington University
Medical Rehabilitation Research & Training Center (RTC#9)
Washington, D.C.

and

Emory University
Regional Rehabilitation Research & Training Center (RTC#6)
Atlanta, Georgia

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INTRODUCTION

Chronic renal failure has been a major health concern in the United States for the past ten years. Early in the decade there was major concern about the treatment of End Stage Renal Disease and the maintenance of life for the renal disabled. Over this ten-year period major advances have been made in medical treatment, dialysis and transplantation.

Financial assistance for medical support has been provided through the Social Security Amendment of 1972. This combination of medical and financial factors has led to a substantial increase in the survival rate of persons disabled with chronic renal failure. During the early 1970's it was projected that there would be 13,000 new cases of End Stage Renal Disease per year. By the end of the decade this number had grown to approximately 50,000 additional cases each year.

With the increase in persons disabled with chronic renal failure, the rate of successful rehabilitation has decreased. This is somewhat remarkable in that several studies have suggested that from 60 percent to 70 percent of the renal disabled can return to former employment or to jobs which can make use of their transferable skills.

In an attempt to learn more about the characteristics of the individual with chronic renal failure and the variables which can be used to predict return to employment, both The George Washington University and Emory University Rehabilitation Research and Training Centers have been conducting research in this area. The research projects have been in progress for more than three years and have begun to furnish data which can improve the vocational decision-making process. Both Research and Training Centers have been providing training to disseminate the results of their research efforts. Unfortunately, staff members of the state rehabilitation agencies have not been able to attend the workshops in sufficient numbers to impact the vocational rehabilitation programs.

To combat this problem, the Research and Training Centers of the two universities joined together to pool staff and resources in sponsoring a National Workshop entitled "Vocational Rehabilitation and End Stage Renal Disease." The two sponsoring research and Training Centers extended an invitation to all state vocational rehabilitation agencies to send one staff member to participate in the workshop. Information on the workshop was also shared with a group of dialysis centers, encouraging them also to enroll staff members in the training program. It was the intent of the course directors to bring together vocational rehabilitation personnel and dialysis center staff to update their knowledge of the treatment and rehabilitation of chronic renal failure and to initiate dialogue between the two groups.

The National Workshop on "Vocational Rehabilitation and End Stage Renal Disease" was held in Denver, Colorado on December 11-13, 1979. The participants, in their evaluations, reported a general concensus that the program was very helpful to them. The following is a report of the proceedings of the Workshop which the course directors hope will be helpful to those professionals who are interested in the vocational rehabilitation of the renal disabled.

Roger S. Decker, Ed.S.
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NATIONAL WORKSHOP

VOCATIONAL REHABILITATION AND END STAGE RENAL DISEASE

Sponsored jointly by
Emory University RTC #6 and The George Washington University RTC #9

December 11-13, 1979

Downtown Holiday Inn
Denver, Colorado

AGENDA

Monday, December 10	
4:00 - 7:00 p.m.	Registration
TUESDAY, DECEMBER 11 DAY I	
7:30 a.m. - 4:00 p.m.	Registration
8:30 a.m.	Welcome - *Irene G. Tamagna, M.D.*
	Introductions - *Roger S. Decker, Ed.S.* *Donald W. Dew, Ed.D.*
8:45 a.m.	Rehabilitation and ESRD: Services with a New Thrust *Kathleen E. Lloyd, M.D.*
9:30 a.m.	Medical Management of the ESRD Patient *Alvin E. Parrish, M.D.*
10:15 a.m.	Coffee Break
10:30 a.m.	Hemodialysis - of Machine and Man *Norman C. Kramer, M.D.*
11:15 a.m.	Adjustment to Dialysis - A Consumer Point of View *John M. Neumann, Ph.D.*
12:00 noon	Questions and Answers
12:15 p.m.	Lunch
1:30 p.m.	Peritoneal Dialysis - As A Long-Term Treatment Modality *Michael I. Sorbin, M.D.*
2:15 p.m.	Transplantation - New Directions and Patient Selection *Israel Penn, M.D.*
3:00 p.m.	Coffee Break
3:15 p.m.	Psychological Issues Relating to Hemodialysis *Peter J. Steinglass, M.D.*
4:00 p.m.	Past Facts and New Futures for ESRD Clients *Eli A. Friedman, M.D.*

WEDNESDAY, DECEMBER 12
DAY II

8:30 a.m.	Introduction - *Donald W. Dew, Ed.D.*
8:40 a.m.	Patient and Family Counseling - Getting It All Together *Peter J. Steinglass, M.D.*
9:30 a.m.	Vocational Potential of ESRD Clients *Helen L. Baker, M.Ed.*
10:00 a.m.	Coffee Break
10:20 a.m.	A Comparison of Long-Term and Short-Term Hemodialysis Clients *Dorothy J. Parker, M.A.*
10:50 a.m.	Utilizing Work Potential - Vocational Assessment and Job Placement *Sheldon Yuspeh, M.S.* *Kalisankar Mallik, M.S., M. Tech.*
11:45 a.m.	Questions and Answers
12:00 noon	Lunch
1:30 p.m.	Sexual Adjustment and ESRD *Gary T. Athelstan, Ph.D.*
2:15 p.m.	Adjustment to Transplantation - A Consumer Response *C. Norman Weaver*
3:00 p.m.	Coffee Break
3:20 p.m.	Counseling the ESRD Patient for Vocational Planning *Elizabeth Rose, B.A.*
4:00 p.m.	Questions and Answers

THURSDAY, DECEMBER 13
DAY III

8:30 a.m.	The Impact of Disincentives on the Rehabilitation of the End Stage Renal Disease Client Panel: *C. Norman Weaver* - Consumer *John M. Newmann, Ph.D.* - Consumer *Hilda Smith, R.N., B.A.* - Social Security Representative

THURSDAY, DECEMBER 13
DAY III (Cont.)

9:45 a.m.	Coffee Break
10:00 a.m.	A Congressional View of Social Security and End Stage Renal Disease *The Honorable Elliott H. Levitas*
11:15 a.m.	Questions and Answers
12:00 noon	Summary and Evaluation
12:15 p.m.	Adjournment

COURSE DIRECTORS

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Rehabilitation and ESRD: Services with a New Thrust

Kathleen E. Lloyd, M.D.
Medical Officer
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Washington, D.C.

Welcome to all of you! I am happy to be in Colorado for an update of our 1974 National ESRD Conference held here, and I bring you greetings from RSA and the NIHR in Washington, D.C.

In the early days of hemodialysis the vocational rehabilitation program in many States had a vital and varied role in providing services of all kinds, electrical, plumbing, etc., to persons with kidney failure. By 1970, approximately 1000 of the 3000 civilians then on dialysis were served in some way by vocational rehabilitation agencies. Since that time, vocational rehabilitation has become less significantly involved. We are searching for the reasons. In general, it is expected that patients receiving home dialysis are at least as well in terms of morbidity and mortality as those who are served in facilities, but the majority of patients, some 89 percent, are now being served in facilities. A 1979 study done by R.W. Evans at Duke University as his Ph.D. dissertation shows no difference in outcome between home and facility when patients are carefully and properly assigned.

It is evident that people on home dialysis are more likely to return to work than those on hospital or facility dialysis. In 1971, 73-83 percent of those employed were on home dialysis. This was probably true for several different reasons: 1) those on home dialysis may be less dependent and more eager to work; 2) possibly home dialysis had been recommended because these persons were in relatively good physical and mental condition; 3) those people on home dialysis could choose their time for treatment and plan to be free to work during normal working hours, not having to fit their treatment time to available facility time; and 4) geographic location may be an important determinant.

Since the National Workshop on VR and Psychosocial Aspects in ESRD in 1974, the role of vocational rehabilitation in serving these persons has lost much of its vitality. In his opening address five years ago, Dr. Joseph Fenton remarked that the new Social Security Amendments, providing financial payment for treatment for the majority of persons with ESRD, should increase the referral of such persons to vocational rehabilitation. Also, many would be the younger people in the more productive years of their lives. So thought we all!

Facts proved otherwise! Once the financial problems were cared for by other means, interest in rehabilitation services seemed to wane and many potential candidates were no longer referred to VR agencies. The result was a tremendous increase in the number of persons receiving hemodialysis, but fewer of these persons were referred to vocational rehabilitation. This also was probably due to several different reasons: 1) the hospital bill was being paid; 2) potential

dialysis patients were no longer carefully screened for other problems and accepted only if their prognosis for possible survival and a satisfactory life were good, so a smaller percentage had a vocational potential; and 3) since disposable supplies were fully paid for in facilities and not in home situations, the cost to the patient personally was less when he went to a facility and generally this was far less upsetting to many family situations. However, this made the patient dependent upon available facility time which frequently meant dialysis had to be performed during the usual working hours of the day and made job-finding difficult, if not impossible, partly because of the high cost in time of travel and the need to fit into facility time.

The net result has been a tremendous increase in actual numbers of dialysis (including persons severely handicapped by other intercurrent problems and diseases, e.g., diabetes, blindness, etc.), but a decrease in relative numbers of persons with vocational potential or interest in work.

We are again in the midst of Social Security changes which we again hope will increase the number of renal patients referred to and rehabilitated by the State agencies. Disposable supplies used in home dialysis are now to be paid for by SSA and it will even be possible, in some instances, to have necessary aides reimbursed by SSA. With these disincentives to home dialysis removed, we hope to see an increase in the current low number of 12.4 percent on home dialysis with a corresponding increase in the number of satisfactory rehabilitations in ESRD.

The latest average costs, as reported by Social Security, are $23,000 per year, per patient in center dialysis and $11,500 for home dialysis.

Physicians working with engineers and other members of the renal team are constantly coming up with new ideas and improved techniques--smaller portable dialyzers, ambulatory peritoneal dialysis, new and improved methods of connecting patient and machine, improving survival rates of kidney transplants, access to and improved availability of healthy kidneys to transplant. All of which should lead to increasing numbers returning to work and more involvement of vocational rehabilitation services.

A limited telephone survey in November 1979, has again raised our hopes that the latest SSA amendment relating to ESRD is working in favor of persons with ESRD who want to work and who could work if they received vocational rehabilitation services. The impression is that while a reasonable number of persons has been evaluated for eligibility and perhaps even provided with services, very few are currently closed rehabilitated. For example, states will report 51 accepted, 6 closed; 33 accepted, 2 closed; and 299 accepted, 22 closed. Of 416 persons served in one region, only 36 were closed rehabilitated, roughly 8.5 percent or one in ten. In other words, many clients are not being successfully rehabilitated or the rehabilitation process is taking an unusually long time and cases are being kept open for long periods. Again, this may be due to the type of patients now on dialysis. In 1971, with a relatively small number of patients, many special programs reported 85-95 percent of those served were employed, while overall reports quoted 50-75 percent. In 1974, the reported average was 27 percent employed.

Some states have a counselor assigned to a dialysis facility to identify and pick up clients with vocational potential and vocational needs, some have cooperative agreements with such programs, and others work closely with Public Health which provides all necessary medical treatments and leaves the rehabilitation personnel free to provide rehabilitation services.

The new Independent Living Program in VR may help to provide a new resource for aid for home dialysis. Homemaker services, both national and international, could be called into use for short term needs, e.g., while a partner is away on business or for a much needed rest. Portable dialyzers can allow for a period of time away from home for either home or facility users and arrangements with dialysis units in distant cities can frequently make the business or pleasure trip a reality.

We hope this week to learn from you of other types of programs and ways of identifying potential VR clients from among the large population now on facility, home, or peritoneal dialysis, and thus improve the opportunities of people with ESRD to return to work.

Medical Management of the ESRD Patient

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Director of Division of Renal Diseases
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Rehabilitation Research & Training Center (RTC #9)
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Kidney disease offers a unique situation in rehabilitation. Medical advances in the last 20 years now make it possible to maintain life in individuals who would otherwise have died of kidney failure using two modalities: the artificial kidney and kidney transplantation, using either kidneys from living, related donors or from accident victims (cadaver donors). Associated with this ability to prolong life, sometimes up to 10 or more years, comes the problem and necessity of returning these individuals to a useful life. Vocational rehabilitation is especially important for these patients because they need to regain their ability to care for themselves and return to productive work.

According to the Department of Health, Education, and Welfare survey ending June 30, 1976, there are 25,000 patients undergoing maintenance dialysis in the United States. There are at least that many in Western Europe. This number is growing at a rate somewhere between 5,000 and 10,000 patients per year and is rapidly resulting in a major economic problem because the cost of maintaining a patient on dialysis is not small.

Normal Kidney Function

The kidneys are essential in maintaining the homeostasis of the body. They regulate the composition and volume of body fluids by conserving essential substances and water and maintaining the body's acid-base balance. The kidneys also detoxify and excrete noxious, foreign, or nonessential materials through the process of urine formation. In addition, the kidney is associated with other functions such as blood pressure control, red blood cell formation, and the metabolism of insulin and other substances.

Each kidney contains approximately one million functional units called nephrons. Each nephron consists of a glomerulus, a Bowman's capsule, and a renal tubule. A glomerulus is a cluster of capillaries. It is partially encased by Bowman's capsule, which extends to form the renal tubule. The renal tubule itself is closely surrounded by capillaries.

The first step in the process of urine formation is glomerular filtration. The blood enters each of the glomeruli through a single afferent arteriole. Within the glomerulus it flows through the capillary cluster. With each passage, about one-fifth of the blood plasma water plus solutes (such as urea, creatinine, glucose, and sodium) filters through the walls of the capillaries into Bowman's capsule. Subsequently this filtrate passes into the renal tubule. Blood cells and blood proteins are too large to pass through the glomerular filter.

The blood components that were not filitered leave the glomerulus through the efferent arteriole, which branches into a second set of capillaries that surround the renal tubule (the peritubular capillaries).

The second step in the process of urine formation is tubular reabsorption and secretion. In the renal tubule, vital substances such as glucose, water, and amino acids are reabsorbed from the original filtrate back into the blood via the peritubular capillaries. At the same time, substances that need to be removed from the blood, such as toxins and metabolic endproducts, which did not all pass through glomerular capillary walls are secreted by the peritubular capillaries into the filitrate in renal tubule. Reabsorption and secretion occur in all portions of the renal tubule by osmosis, diffusion, and active transport. The filtrate, which is now called urine, leaves the renal tubule and enters a collecting tubule. The collecting tubules join increasingly larger tubules. Eventually all final tubules discharge urine into the renal pelvis, from which it passes down into the ureter and into the bladder where it is stored until eliminated during urination.

When the kidney fails, one or all of its functions fail. Early manifestations of kidney failure may be so slight as to go unnoticed. Usually they result from a decrease in the glomerular filtration and tubular secretion processes, leading to a decrease in concentration of noxious substances and, hence, an increase in urine flow (polyuria), especially at night (nocturia) in order to remove solutes. Later an elevated blood pressure may develop. Still later the filtering process fails further so that not even water is filtered well. Urine volume then decreases and the condition of uremia is present. At this stage, dialysis or transplantation becomes necessary because there is no longer an effective means of removing toxic substances as fast as they are produced.

The glomerular filtration rate (GFR) is the amount of filtrate passed through the glomerular capillary walls per minute. It is usually estimated by determining the amount of creatinine, a metabolic endproduct, that is discharged into the urine per minute. Since the concentration of creatinine in the filtrate is almost the same as in the blood, the volume of filtrate passed can be calculated as follows:

$$\text{GFR} = \text{amount of filtrate per minute } \frac{(\text{ml})}{(\text{min})} = \frac{\text{amount of creatinine excreted in urine per minute}}{\text{concentration of creatinine in blood serum}} \frac{(\text{mg/min})}{(\text{mg/ml})}$$

If kidney damage occurs, then filtering decreases and the GFR decreases. Further, in kidney disease, creatinine itself is not excreted well, so that the concentration of serum creatinine increases. Table 2 demonstrates the classification of renal function based on GFR and serum creatinine. If serum creatinine exceeds 8 mg/100ml (mg%) and/or GFR is less than 10 percent of normal, then dialysis is usually required.

Etilogy

Table 1 lists a variety of diseases of the kidney which may result in end-stage renal disease. Kidney disease may affect any age group. Some forms may by inherited and others, even though not inherited, may have had the onset in childhood. The most common kidney diseases are limited to those related to high blood pressure (hypertension), polycystic disease of the kidney, and glomerulonephritis. The symptom complex exhibited by patients with end stage renal disease is the same without regard to the basic kidney disease, and the actual cause of the disease is usually of secondary importance, except in a few instances such as diabetes or lupus erythematosus.

Diabetes, through its effect on the vascular system, may involve the kidney sufficiently to cause kidney failure. The prognosis is usually worse than in other forms of kidney failure because of the vascular complications affecting other systems.

Similarly, lupus erythematosus involving the kidney also has a poor prognosis because of the involvement of the basic disease with other systems.

End stage renal disease may develop rapidly, as occurs in rapidly progressive glomerulonephritis, so that treatment with the artificial kidney is begun soon after the initial onset of renal disease. The onset of kidney failure more frequently does not occur until years after the beginning of kidney disease. In inherited diseases of the kidney such as polycystic disease, renal failure may not begin until the individual is in his 30's or 40's.

Signs and Symptoms

The term uremia is used to describe the clinical symptoms of end stage renal disease. Since uremia is a generalized metabolic abnormality, these symptoms usually involve all systems of the body. Symptoms and signs may include: decreased urine output, anemia, osteoporosis, heart failure, ulcers, bleeding from the stomach, mouth, or rectum, loss of appetite, lethargy, nausea, vomiting, swelling of the legs or entire body, loss of memory, difficulty in concentrating, peripheral nueropathy with weakness and sensory loss, sexual dysfunction, and occasionally coma and convulsions.

The earliest signs of kidney failure are often an inability to concentrate and a shortened attention span. As a result, individuals with failing kidneys who have jobs that require mental, rather than physical, exertion may quit their jobs to take less exacting ones or be fired for their inability to keep up with their work before it is recognized that kidney failure is the cause. As kidney failure becomes more severe, physical impairment becomes more predominant, with increasing inability to eat, weight loss, weakness, and easy fatigability. It is then that the individual whose occupation requires more physical activity begins to have difficulty and may lose or quit his job.

Of various signs and symptoms, anemia, osteoporosis, and peripheral neuropathy need special attention.

Anemia. Anemia is a usual finding in uremia and is the result of the diseased kidney's inability to produce erythropoietin, the hormone necessary for blood formation. The anemia seems to be an important part of the physical weakness that accompanies kidney failure, but not the only cause.

Blood transfusions help but have the added risk of further depressing blood formation and of transmitting hepatitis. Type B infectious hepatitis appears to be transmitted by blood from infected individuals or carriers, and, therefore, may follow blood transfusion. It can also be transmitted by contact with the blood or secretions of infected or carrier patients and, therefore, can even spread in a dialysis center from patient to patient and to staff. Consequently, nephrologists tend to give as little blood as possible.

Peripheral neuropathy. Involvement of nerves in the hands and feet due to uremia may eventually lead to peripheral neuropathy with loss of sensation and weakness in the arms and legs. Subsequent paralysis may be so severe as to make the individual bedridden. Involvement of the autonomic nervous system may lead to diarrhea, fainting or standing, and sexual impotence.

Except for adapting around the disability of hand or leg weakness, no specific treatment exists, although neuropathy is inclined to clear with dialysis or transplantation.

Hyperparathyroidism and osteoporosis. In kidney failure, the parathyroid glands become overactive. These glands, located in the neck, normally help to control phosphate and calcium in the blood and bone. When they become hyperactive, there is a loss of calcium from bone (osteoporosis) and deposition of calcium in places other than bone, including the skin. This increased parathyroid gland activity, together with the failure of the body to utilize vitamin D properly, may lead to bone pain and, occasionally, bone factures. Deposition of calcium in the skin seems to be associated with intense itching.

The treatment of this secondary hyperparathyroidism is the removal of part or all of the glands. Prevention of this complication is difficult, but is partially aided by aluminum hydroxide taken orally to reduce blood phosphorous.

FUNCTIONAL DISABILITIES

Functional disabilities in patients with renal failure can be quite variable. A classification system established by the American Heart Association is shown in table 2. This table is very useful in categorizing the functional problems associated with renal disease, and can serve as a useful guide for counselors.

This classification divides patient evaluation into three categories: (a) Symptoms (Roman numerals); (b) Renal function (letters); and (c) Performance (Arabic numerals). Each of these is divided into five to six levels of increasing

severity of impairment. Thus, an asymptomatic individual with good function and no physical impairment would be classified as class I-A-1, whereas a severely ill person with no kidney function and in coma would be class V-F-5. This classification is being used by more and more nephrologists, and receiving a patient with such a classification will help the counselor determine the degree of disability. Most patients who require dialysis or transplantation will be class III-E-3 or greater.

For the most part, the consideration of rehabilitation begins once hemodialysis with the artificial kidney is started. Most patients receiving maintenance dialysis will be classified no better than II-F-1 or II-F-2.

Physical Disabilities

An individual with peripheral neuropathy may have problems in walking due to "foot drop" and may also have paralysis of one or both hands. Grip strength and hand skills such as writing may be impaired. Further, ambulation, stair climbing, and balance may be impaired. With adequate dialysis, the patient's condition may improve, but this may require months to accomplish and recovery may be incomplete.

The presence of anemia impairs the individual's ability to perform physical activities, with the degree of disability related to the severity of the anemia. It is not unusual to see anemia in renal failure with blood counts reduced 50 percent or more. These individuals become short of breath at minimal exertion and often complain of weakness, easy fatigability, and lack of stamina requiring them to be more sedentary.

Intellectual Disabilities

Uremia, through mechanisms which are at present unknown, may interfere with the function of the brain. As a result, uremic patients may have difficulty in concentration and in prolonged mental effort. This is almost always associated with either inadequate dialysis or no dialysis at all, and is usually quickly corrected by treatment with the artificial kidney.

Psychosocial Disabilities

Pre-existing problems such as marital discord are usually magnified by maintenance dialysis. The patient's spouse may be unable to adapt to the problems of end-stage renal disease and the marriage may disintegrate. The patient's family may desert him, refusing to take him home even when he is capable of caring for himself. They may even refuse to allow him to go to limited care centers for hemodialysis or accept a kidney transplant.

In some reported groups of patients, the amount of emotional adjustment was related to IQ, with poorer adjustments occurring in those individuals with lower IQ.

Individuals with end stage renal disease frequently show signs of psychological disturbances as a result of the disease and its treatment. The management of patients with kidney failure includes intensive medical care, close association with nurses and doctors, and loss of large amounts of time while receiving dialysis. This degree of care extends over a period of months or years and usually continues for the rest of the patient's life. As a result, he may display defense mechanisms and develop varying degrees of dependence, feelings

of uselessness, hostility, and depression. The manifestations of these disturbances may take a number of forms.

Defense mechanisms. The most common defense mechanism is denial, the patient's failure to recognize the fact that he is ill. Another frequently observed mechanism is projection. The individual acribes symptoms to others and can talk about these, but he cannot comfortably discuss his own symptoms. He may also become overly concerned with the minutia instead of the major problems (displacement). Finally, he may behave in a manner opposite to his true feelings (reaction formation). He may hate the doctor but be congenial and cooperative. A patient using this mechanism may need psychiatric help, if the mechanism is sufficiently exaggerated.

Dependence. It is very easy for a critically ill person to become dependent on family members and medical personnel for both physical and emotional support. This is normal to a degree, but can become so extreme that the person loses motivation to do anything for himself, including caring for his personal hygiene. This is most apt to happen to individuals with low-paying jobs, and is often augmented by the fact that medical care is supported by Federal, state, or private agencies. The individual may quit him job or ask for retirement, sometimes without telling the medical staff. Once he has started this pattern, it may be impossible to change it and he becomes entirely dependent on his family and the medical staff.

Feelings of uselessness. The physical disabilities accompanying kidney failure, the necessity for frequent dialysis, and the attentiveness of the family and medical and social personnel often made the patient feel as if he no longer has any useful role in life. Impotency in males and physical weakness augment this.

Hostility. Individuals with chronic kidney failure may express their frustration with their debility by becoming hostile to the personnel trying to help them. This may take the form of noncompliance with medical management and include over-consumption of liquids or foods they should avoid, failure to take medication, or failure to show up for dialysis. Hostility is occasionally manifested as open aggression. It may result in the individual having multiple complaints about personnel, the dialysis center, or his family. It may also result in reaction formation, as above.

Depression. Depression may be exhibited as part of all manifestations of disturbance and as a lack of motivation. The patient begins to realize the future implications of his disease, that he will be under some sort of treatment for the rest of his life, and that this treatment will seriously interfere with his usual life style.

Psychological and social counseling and/or psychiatric treatment may be indicated when the above emotional difficulties become extreme.

Rehabilitation Potential

Patients falling into a classification of II-F-3, 4, 5, or worse (Table 2) have sufficient disability to require rehabilitation efforts. The first requirement

in the reversal of disability is either adequate hemodialysis or kidney transplantation plus maximal control of the ancillary diseases such as heart disease, hypertension, and infection. The goal of medical treatment is to advance the patient to the levels of Performance Class 1 or 2. Once at that level, vocational rehabilitation and a return to a useful life can commence in earnest.

Individuals in class II-F-1 or II-F-2 can usually return to their previous life style. Those who had sedentary jobs or did not undertake strenuous activities prior to becoming ill can most likely return to their jobs, even if they are in Performance Class 2. If, however, their activities require more physical activity than they are capable of, their life style or occupation will need to be changed. Appropriate vocational counseling and, possibly, retraining then become critical to success.

In Performance Classifications 1 and 2, psychosocial problems become predominant and may significantly interfere with rehabilitation. In addition, previous work experiences, intelligence level, and the possibility of secondary gain, all influence the degree of return to normal life that can be achieved.

Secondary gain may be an important factor in rehabilitation failure. It may be to the patient's advantage to remain on dialysis and reject the potential "cure" of a transplant, if he gains the support of his spouse in a faltering marriage. Prolonged illness may be of economical benefit to the patient. He received his medical care and may receive financial assistance sufficient to allow him to support his family without working. If the patient is a wife or child, the family may receive funds in excess of their ordinary income. Often, especially in low-paying jobs, it may seem more "worthwhile" for the patient to receive a disability retirement than to continue working. This removes all further incentive and attempts at rehabilitation fail.

STANDARDS OF EVALUATION

For the proper assessment of the status of an individual with renal disease, an accurate diagnosis must be made. It is important to recognize that some causes of kidney failure are reversible and a long and complicated program of dialysis or transplantation may not be necessary. Such diseases as vasomotor nephropathy (also called acute tubular necrosis, lower nephron nephrosis, hemoglobinuric nephrosis, shock kidney), obstructive uropathy, acute glomerulonephritis, and acute pyelonephritis (see glossary) are reversible in most instances, leading to either complete or almost complete recovery in less than 6 months.

The most common methods for evaluating individuals with kidney disease are:

1. Careful history and physical examination

2. Urinalysis, with special attention to the urinary sediment and protein content.

3. X-ray, either an intravenous pyelogram or a retrograde pyelogram

4. Kidney biopsy

5. Creatinine clearance

All of these studies are usually performed under the direction of the nephrologist or internist, who should remain the primary physician. Any problems suspected later by the counselor or others should be referred to the primary physician.

The clinical course of the illness usually helps to distinguish reversible from nonreversible disease. The individual who has been ill for some time most likely will show a course progressive to the state of uremia over a period varying from months to years. X-ray and/or biopsy may be helpful in determining the cause of uremia, but biopsy may not be necessary. The degree of uremia is usually estimated by measuring the patient's blook urea nitrogen (BUN) or creatinine.

The sudden appearance of uremia without a previous history of known kidney disease requires careful medical evaluation. Intravenous or retrograde pyelography is almost essential to establish the diagnosis and prognosis. Consultation with a urologist is essential where obstruction to urine flow is suspected. Once it has been determined that the individual has end stage renal disease, the degree of functional impairment can be further defined by kidney function tests and by evaluation of physical, psychosocial, and vocational capabilities.

The kidney function tests most useful in estimating kidney function are the glomerular filtration rate (GFR) of the kidney and the concentration of creatinine in the blood. Both serve as a basis for the classification of renal function seen in Table 2.

Before entering into a dialysis or transplant program, the individual should be further evaluated as follows:

1. A psychologist or psychiatrist familiar with the problems of end stage renal disease should interview the patient. The Wechsler Adult Intelligence Scale (WAIS) or the Minnesota Multisphasic Personality Inventory (MMPI) may be helpful.

2. A social worker's evaluation of the family structure, housing, and finances is critical. The latter is of special importance, since under Public Law 92-603 most persons can have their medical expenses paid by the Social Security Administration if proper application is made.

3. A vocational evaluation that includes current employment requirements, employer attitudes, prior job history, and education is necessary to assist in planning.

4. A neurological evaluation that includes nerve conduction velocity measurements may be helpful.

5. A dietary evaluation and consultation with the patient and his family, unless a regular diet is allowed, may ensure patient compliance.

If, in the course of these evaluations, significant psychiatric, neurological, or other medical problems are discovered, the patient should be seen in consultation by the appropriate specialists, which may include a urologist, psychiatrist, and/or transplant surgeon. Again these studies and consultations should be arranged by the primary physician, usually the internist or nephrologist.

Finally, all of the information gathered by the various specialists should be discussed by the physicians, nurses, social workers, and counselors to develop a plan for the management of the patient's problems. Most of these steps in evaluation are now required by federal regulation (see bibliography) and are in operation at approved end stage renal disease treatment centers.

VOCATIONAL IMPLICATIONS

Individuals with end stage renal disease may have both mental and physical problems even though they are receiving treatment with regular maintenance dialysis, and may continue to have these problems after kidney transplantation. Vocational rehabilitation in end stage renal disease begins once treatment for kidney failure has been started. It can only become effective when medical treatment has improved the individual's physical status to a level where he is essentially independent in his personal care. It must be accompanied by a positive attitude that the individual will return to an active, productive life. Rehabilitation needs to be undertaken aggressively with speed, sympathy, and encouragement.

Table -1. Usual diseases resulting in kidney failure

Glomerulonephritis	37%*
Vascular Disease	24%
Nephrosclerosis	
Malignant hypertension	
Interstitial Nephritis	15%
Pyelonephritis	
Analgesic abuse	
Drug toxicity	
Diabetes	7%
Polycystic Disease	7%
Other Congenital Diseases	2%
Other Diseases	8%

* Incidence at The George Washington University Medical Center

Table -2. Criteria for the evaluation of the severity of established renal disease prepared by the Council on the Kidney in Cardiovascular Disease, American Heart Association.

CLASSIFICATION OF SIGNS AND SYMPTOMS BY SEVERITY

Class I: Requires (a) plus one or more of (b) through (f):

(a) No symptoms directly referable to renal disease
(b) Fixed proteinuria (>200 mg/24 hours)
(c) Repeatedly abnormal urine sediment or bacteriuria in properly obtained urine specimens
(d) Demonstrable radiographic abnormality of the upper GI tract
(e) Hypertension attributable to past or active renal disease
(f) Biopsy-proven parenchymal renal disease

Class II: Any two or more of the following:

(a) Symptomatic because of symptoms directly referable to the kidney (e.g., hypoproteinemia edema, dysuria, flank pain, renal colic, nocturia)
(b) Radiographic evidence of osteodystrophy
(c) Stable anemia attributable to renal disease
(d) Metabolic acidosis attributable to renal disease
(e) Severe hypertension (diastolic BP>110 mm. Hg)

Class III: Any two or more of the following:

(a) Symptomatic osteodystrophy
(b) Symptomatic peripheral neuropathy
(c) Nausea and vomiting without primary GI cause
(d) Limited ability to conserve or excrete usual dietary load of sodium and water; tending to sodium depletion, dehydration or congestive heart failure
(e) Impaired mentation attributable to renal disease

Class IV: Any two or more of the following:

(a) Uremic pericarditis
(b) Uremic bleeding diathesis
(c) Asterixis and severely impaired mentation, with or without convulsion
(d) Hypocalcemic tetany

Class V: Coma

Table -2. Continued

CLASSIFICATION OF RENAL FUNCTIONAL IMPAIRMENT

	Primary	Secondary
Class A:	GFR normal	Serum creatinine normal 0.6-1.3 mg% *
Class B:	GFR still > 50% of normal	Serum creatinine normal to 2.4 mg%
Class C:	GFR 20-50% of predicted normal	Serum creatinine 2.5-4.9 mg%
Class D:	GFR 10-20% of predicted normal	Serum creatinine 5.0-7.9 mg%
Class E:	GFR < 10% of predicted normal	Serum creatinine 8-12 mg%
Class F:	GFR < 5% of predicted normal	Serum creatinine >12 mg%

* mg% means mg/100 ml serum

PERFORMANCE CLASSIFICATION

Class 1: Capable of performing all usual types of physical activity
Class 2: Unable to perform the most strenuous of usual types of physical activity for that particular patient, e.g., sports activity, fast walking, running, shoveling, lawn mowing
Class 3: Unable to perform all usual daily physical activities on more than a part-time basis, e.g., household duties, employment, driving an automobile, playing with children
Class 4: Severe limitation of usual physical activity; may need assistance for some facets of self-care, e.g., shaving; mentation may or may not be impaired
Class 5: Semicoma or coma

Hemodialysis - of Machine and Man

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When renal function fails to keep up with the excretion of waste material produced by the body, the syndrome of uremia develops and a series of symptoms and body changes develop which require management.

Steps in the care of an individual with chronic renal disease include:

1) Pre-dialysis conservate treatment

   a) Diet regulation
   b) Control of blood pressure
   c) Conservation of existing renal function

2) Replacement therapy

   a) Hemodialysis
   b) Peritoneal dialysis
   c) Transplantation

Hemodialysis

The hemodialyzer, or artificial kidney as it is called, can perform some, but not all, of the functions of natural kidneys. The artificial kidney can remove waste metabolites and water and maintain chemical equilibrium sufficiently to return the patient to nearly normal condition for several days. Dialyzers operate outside the patient's body to dialyze or cleanse the blood of the patient. The blood is usually drawn from a tube in an artery and, after passing through the dialyzer, is returned through a tube inserted in a vein.

What makes it possible to use only the blood in order to restore the patient to a nearly normal condition? As it flows through the body, the blood collects waste materials and excess water that are discharged when the blood reaches the kidney. The kidneys act as a regulating mechanism by determining how much of the various waste materials, chemicals, and water to remove in order to maintain a normal, healthy condition. By effectively removing these various materials from the blood, the dialyzer temporarily replaces the function of the natural kidneys and is able to keep the patient close to a normal condition. Just how the dialyzer performs each of its separate functions is described in the following paragraphs.

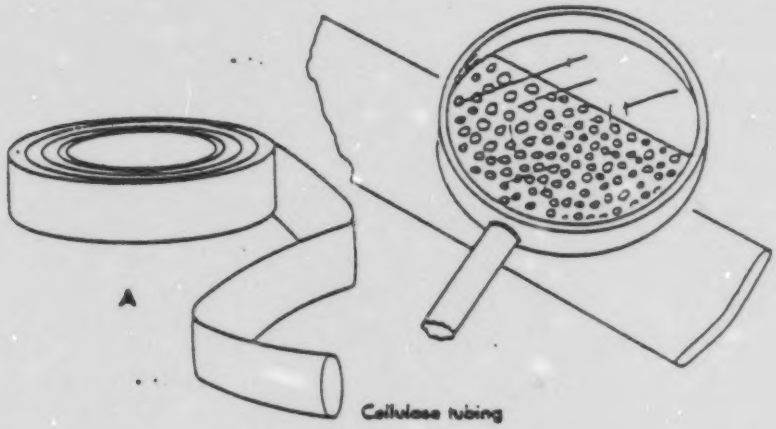
Waste products are defined as the unusable end products of metabolism. Metabolism is the process by which food is converted to energy and structural components for the body. The waste products from metabolism accumulate in the bloodstream

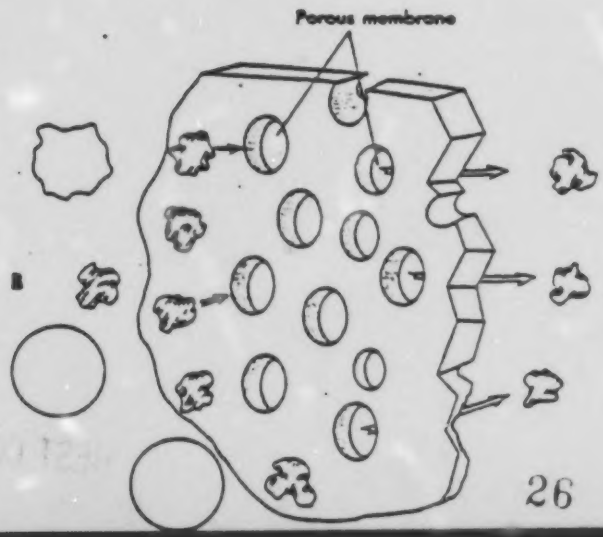
and, during normal renal function, are eventually removed when the blood passes through the kidneys. As a partial substitute for disabled kidneys, the dialyzer removes these waste products by the process of dialysis.

Dialysis involves the use of a think, porous membrane (cellulose) that keeps the blood separated from another fluid, the dialysate, in the dialyzer.

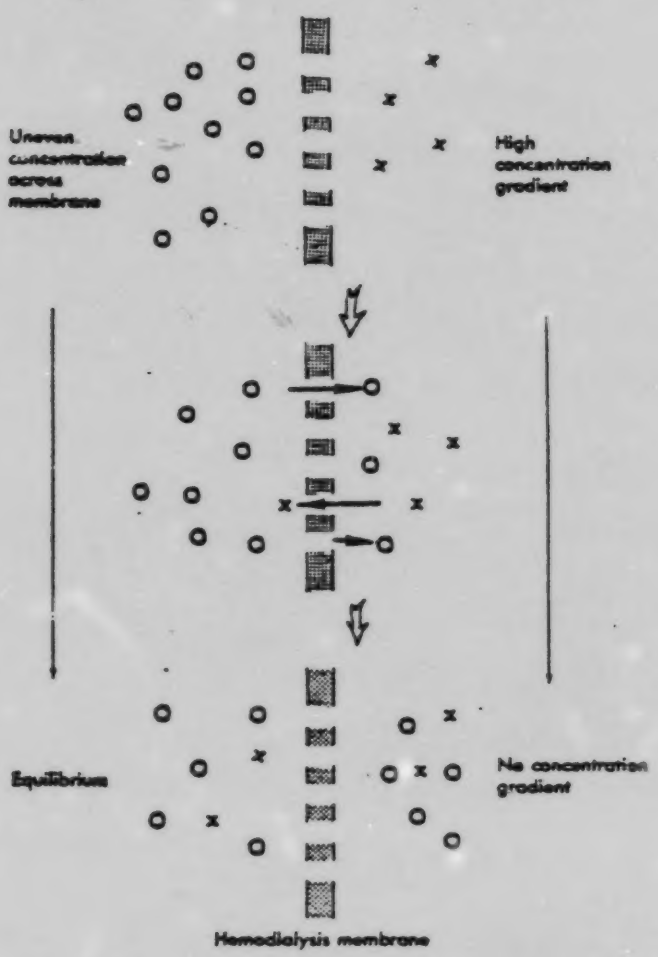
The membrane can be compared to a metal netting. Like the metal netting, the membrane has perforations, but they are so extremely small that they are invisible to the naked eye. Waste products in the blood are able to pass through these minute performations into the dialysate fluid where they are immediately washed away. The perforations in the dialysis membrane have an average diameter of 50 A, with an estimated range of 30 A to 90 A.

The waste products (as molecules) pass through the membrane by action of a concentration gradient. All molecules move in a random manner when they occupy a given volume, and in so doing they tend to distribute themselves evenly throughout the entire volume. The number of molecules in a specific volume is the concentration. In the artificial kidney, the dialysate fluid is free of waste product molecules; consequently, those in the blood are able to pass through the membrane and tend to distribute themselves evenly throughout the blood and the dialysate. Thus, there is a net movement of waste product molecules from the region of high concentration (the blood) to a region of low concentration (the dialysate). This difference in concentrations between the blood and the dialysate, which is the cause of the movement of molecules, is known as the concentration gradient.





There are many different types, as well as sizes, of particles (molecules) in the blood. These molecules include the waste products such as urea, creatinine, and uric acid, ions (small particles that have an electric charge), and many other larger molecules. In addition to the proteins, there are even larger particles (such as erythrocytes and leukocytes) that are the formed elements of the blood. These blood cells, along with the majority of the proteins, do not pass through the membrane during dialysis; they are just too large for the perforations in the membrane. This selective quality of the membrane -- allowing small molecules to pass through but retarding the passage of progressively larger molecules and particles--represents the real advantage of dialysis. Proteins, erythrocytes, and leukocytes are invaluable to the body, and their loss would have fatal consequences for the patient. Because the membrane can effectively retain these larger substances and at the same time eliminate unwanted waste materials from the blood, dialysis has become an effective agent in the treatment of renal diseases. Furthermore, no bacteria or viruses can be introduced into the blood compartment, because they are too large to pass through the perforations in the dialysis membrane.



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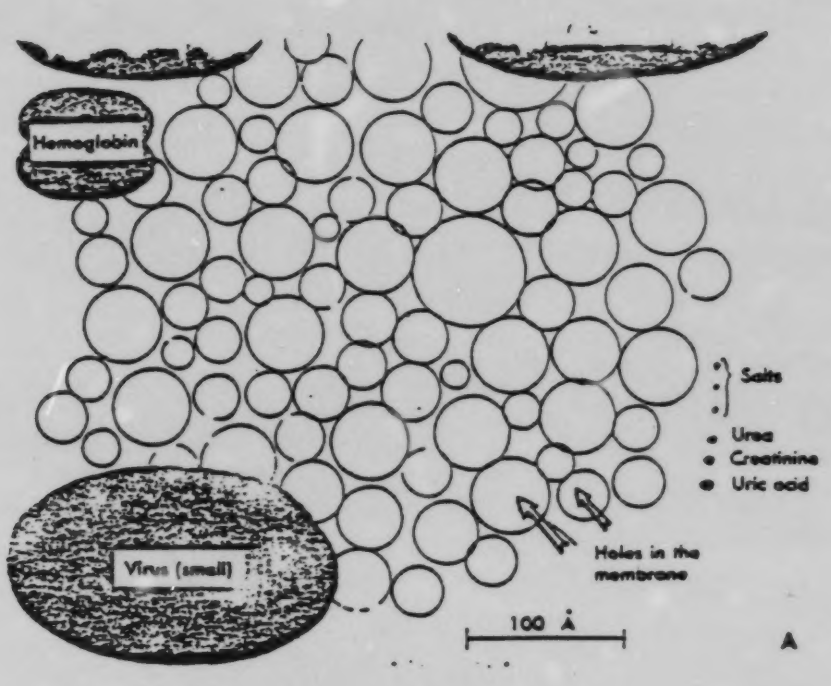
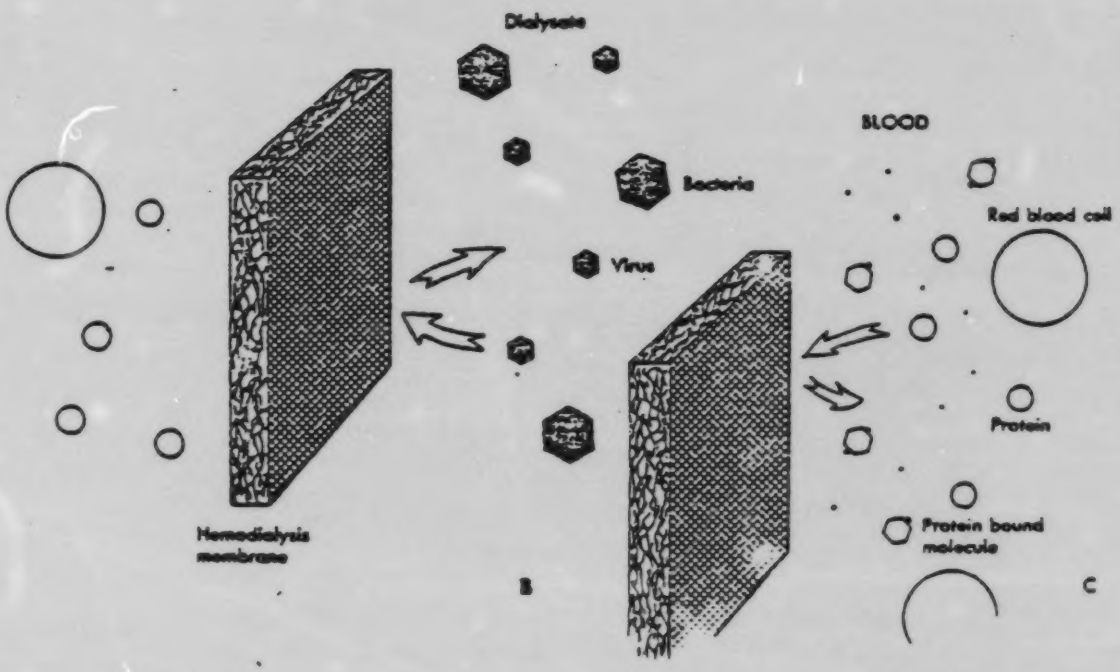


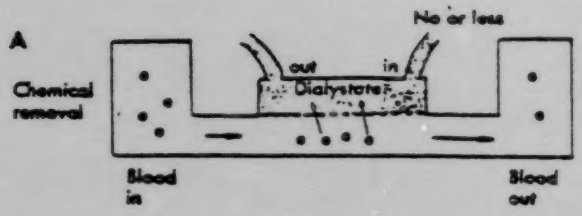


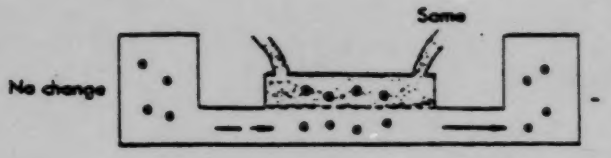
Molecules in the blood

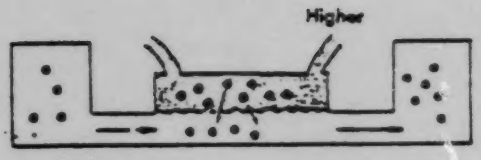
Molecules	Molecular weight
Electrolytes	
Sodium	22.989
Chloride	35.453
Potassium	39.102
Calcium	40.08
Magnesium	24.312
Urea	60.06
Creatinine	113.14
Uric acid	168.11
Dextrose	180.16
Bilirubin	584.67
Amino acids	
Glycine (smallest	75.07*
Tryptophane (largest)	204.22*
Protein	
Albumin	68,000
-globulin	150,000
Hemoglobin	68,000
Fibrinogen	400,000

*Will combine with protein (see Fig. 2-3).

Many chemicals are present in all parts of the human body. These chemicals appear in several forms--compounds, ions, and aggregates. Aside frwm their presence, the relative amounts of each are critically important to normal body function. As an example, potassium is present both in the body cells and in extracellular fluid such as blood. There is a definite relationship between the amount of potassium in the blood and the corresponding amount in the body cells. As found in the blood, the ionic form of potassium is minute and can easily pass through the dialysis membrane into the dialysate fluid. If the dialysis were performed with dialysate that contained no potassium, the amount of potassium in the blood would steadily decrease. The ratio between the amount of potassium in the body cells and in the blood would consequently be upset, and the effects could be dangerous. For actual practice, no potassium baths for hemodialysis on uremic patients are used without any danger. However, these imbalances are avoided by the addition of chemicals to the dialysate fluid to make their concentration the same as that concentration in the blood. With no concentration gradient, there is no net movement of these critically important chemicals through the pores of the dialysis membrane. Thus, valuable chemicals small enough to pass through the pores of the dialysis membrane are retained in the blood. Conversely, when body balance of some vital chemical is upset as a result of disease, it may be restored by properly adjusting the concentration of the chemical in the dialysate fluid. When it is desirable to remove an excess of the chemical from the blood, the chemical is not added to the dialysate fluid. This will produce a large concentration gradient favoring net movement of the chemical from the blood to the dialysate. To add a given chemical to the blood, the procedure would simply be reversed.

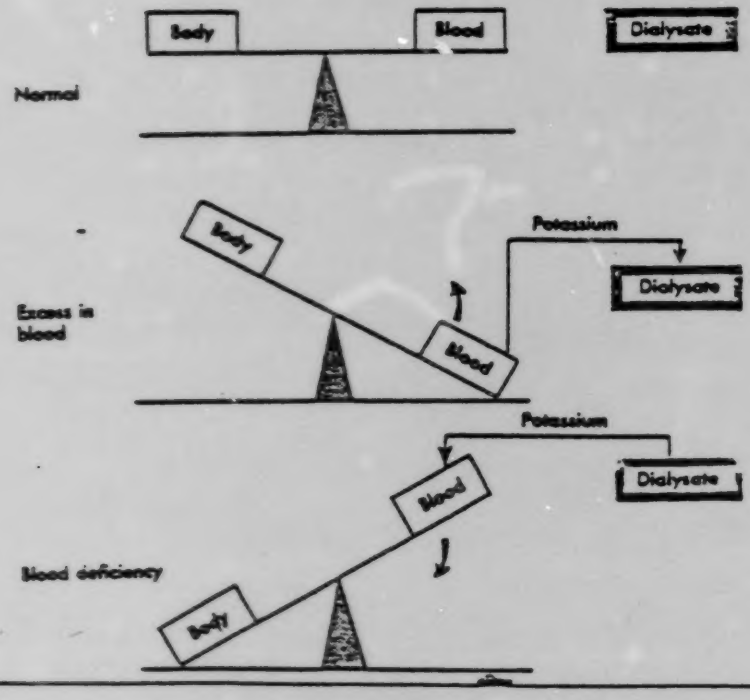






Potassium chemical balance

B



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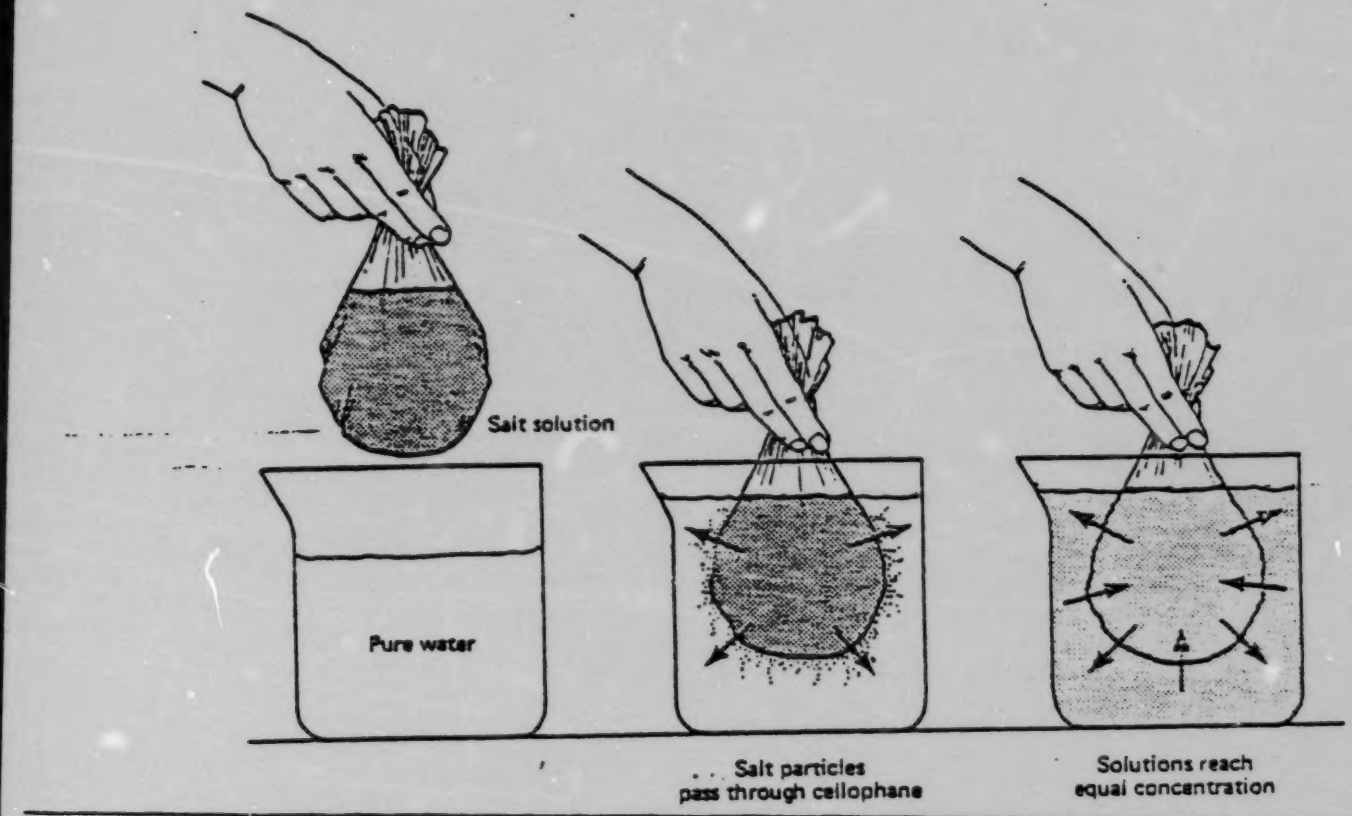
Water molecules are extremely small and pass easily through the pores of the dialysis membrane. The term "water concentration" may be thought of as the percentage of water molecules in a specific volume containing many different molecules. All other molecules and particles dispersed among the water molecules are known as solutes, and the water is called the solvent. The two together are referred to as a solution. If the number of solutes is significantly increased, the water concentration is decreased. In practice the above principle is one basis for removing excess water from the blood during dialysis. There are two methods of water removal, addition of a substance to the dialysate fluid and ultrafiltration.

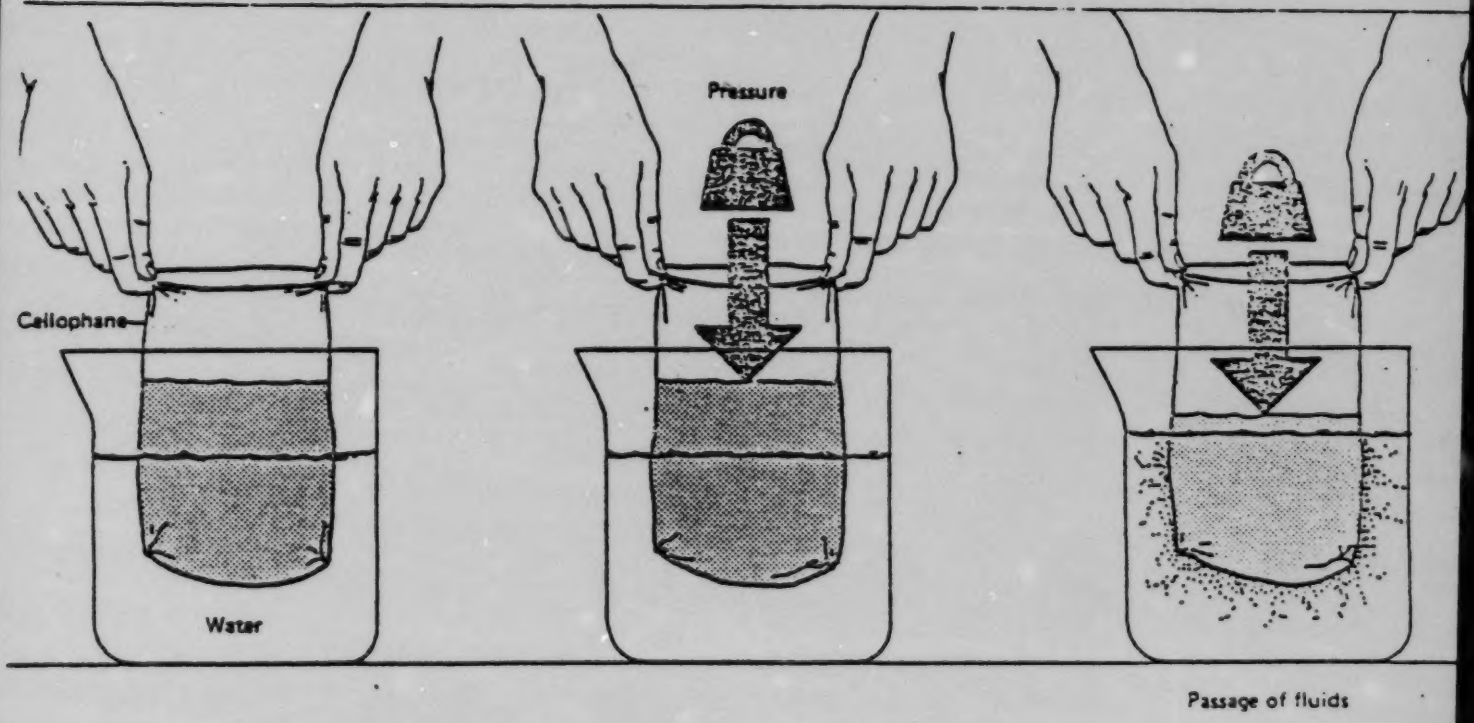
A large amount of some harmless substance, such as dextrose, is added to the dialysate fluid to decrease the water concentration. Because the water concentration in the blood is higher than that in the dialysate fluid, a concentration gradient is set up that results in a net movement of water out of the blood into the dialysate fluid. This phenomenon is commonly referred to as osmosis.

Excess water is usually removed from the blood by another process known as ultrafiltration. This process is more effective than the addition of dextrose to the dialysate. Ultrafiltration of water through a dialysis membrane works on the principle of pressure differences. In order to make water flow through a pipe or other conduit, the pressure applied to the fluid at the upstream end of the pipe must be greater than the pressure at the downstream end. One can imagine an analogous situation in the artificial kidney during dialysis. Blood and dialysate flow through a compartment, separated from each other by the dialysis membrane. Since the water molecules of both the blood and the dialysate fluid can easily pass through the membrane, the direction of flow will be primarily determined by the pressure difference. At points along the membrane length, when the pressure on the blood is greater than the opposite pressure on the dialysate fluid, the water flows from the blood into the dialysate. When the situation is reversed, water flows from the dialysate into the blood.

Since ultrafiltration is a much more effective means of removing excess water than is omosis, it is usually favored if practical. The pressure differences in the dialyzer can be adjusted to remove variable amounts of excess water.

29
Diffusion





Passage of fluids

Several points should be made in regard to optimum performance of the various types of dialyzers.

The metabolite clearance (MC) is a measure of the removal rate of waste products. The mathematical equation

$$MC = \frac{C_1 - C_2}{C_1} Q_B, \text{ ml./min.}$$

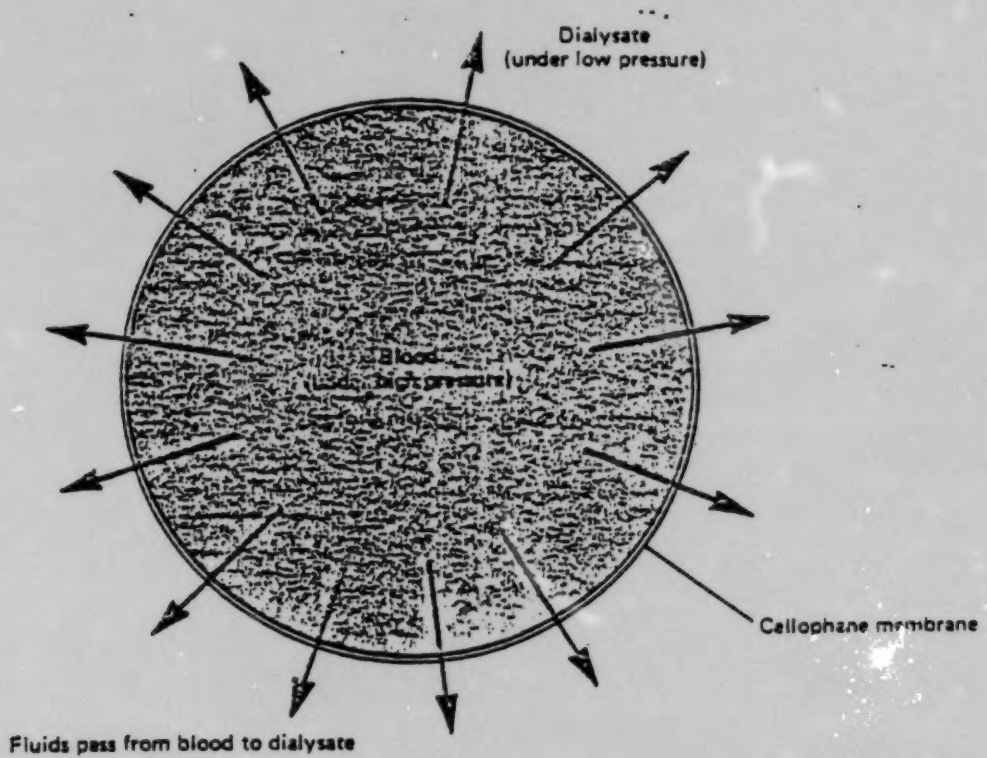
where C_1 = blood inlet concentration of waste product from the dialyzer, C_2 = blood outlet concentration of waste product fromthe dialyzer, and Q_B = blood flow rate, shows that waste product removal depends on, or is a function of, the blood flow and the fractional change in waste product concentration as the blood passes through the dialyzer. The magnitude of these quantities, in turn, depends upon such physiologic factors as blood pressure and blood vessel patency, as well as on physical factors such as blood film thickness and resistance, dialysate flow rate, and membrane form and permeability. Optimizing the metabolite clearance of any dialyzer requires manipulation of these factors until a satisfactory waste removal rate has been established. In many cases, variables will themselves depend upon other variables, and often compromises will have to be made between opposing factors to achieve optimum efficiency of the dialyzer. Ultrafiltration (ml./hr) is just as important in many patients as is waste product removal. Often, however, conditions for good ultrafiltration are in opposition to adequate waste product removal. For example, in a continuous-flow dialyzer, when a patient requires little or no water removal, the dialysate is generally pumped through the dialyzer. If more water removal is necessary, the dialysate is sucked through the dialyzer. Sucking creates a negative pressure in the dialysate. ("Negative pressure" refers to a pressure that is less than the normal atmospheric pressure.) The effect of this negative pressure is to increase the pressure difference between the blood and the dialysate, thereby increasing the rate of water removal. However, the same increase in pressure difference that increases ultrafiltration increases the priming volume and blood film thickness and, consequently, reduces the waste metabolite removal. It is important to recognize that many of the physiologic and physical variables affecting dialysis (waste removal) also affect ultrafiltration and vice versa. A dialyzer capable of a urea clearance of over 80 or 90 ml./min. at a flow rate of 150 ml./min. and ultrafiltration of over 150 ml./hr. is ideal.

Conditions for an effective dialyzer (optimal metabolite clearance)

1. Large surface area of membrane
2. Good dailysis membrane
3. Small, constant priming volume
4. Thin channel for blood
5. Even distribution of blood
6. Short channel for blood
7. Effective mixing of blood
8. High blood pressure (if a blood pump is not used)
9. High blood flow
10. Fresh dialysate and effective dialysate flow
11. Countercurrent flow of dialysate and blood
12. High flow rate of dialysate

13. Effective exposure of the dialysis membrane to the dialysate
14. High temperature of dialysate

Ultrafiltration during dialysis

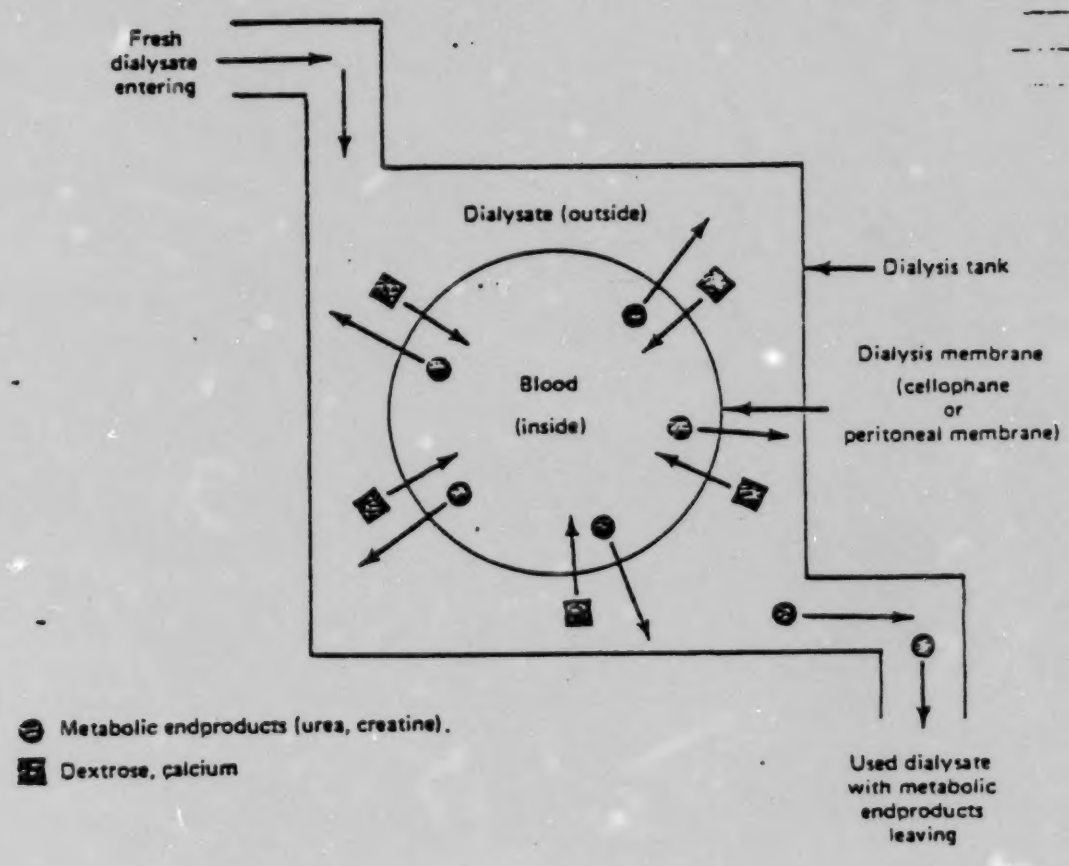


The principle of hemodialysis was described by Abel, Rowntree, and Turner in 1913. They reasoned that it might be possible to remove toxic materials by the process of external diaylsis of blood and thus obviate the grave danger in case of renal failure. They devised a vividiffusion apparatus. To avoid the clotting of blood in an extracorporeal circuit, they used hirudin and celloidin (collodion) tubes as their membrane. Blood entered the manifold at both ends and flowed through the celloidin membranes. Outside the celloidin tubing the rinsing solution circulated. In 1926, Lim and Necheles used heparin as an anticoagulant for hemodialysis. By 1933, heparin had been purified and in 1937, Thalhimer used it for hemodialysis. Thalhimer also introduced cellulose tubing--a seamless sausage casing--for hemodialysis. In 1943, Kolff developed the rotating drum artificial kidney and used it clinically. After that, several other types of dialyzers were introduced. These can be classified as: the coil artificial kidney, such as Alwall developed in Sweden in 1947, which has cellophane tubing would around wire screen; the Kolff twin coil artificial kidney (1956), which is based upon the Von Garrelts stationary coil artificial kidney developed in Sweden (1947) and later modified by Inouye and Engelberg (1953); or the plate type of artificial kidney such as the MacNeill (1949), Skeggs and Leonards (1948), Esmond (1966), Galletti (1962), and Kiil (1960). Regardless of the type of artificial kidney, the membrane used for

hemodialysis is made from cellulose and called either Visking Cellulose (Union Carbide) or Cuprophan Membrane (J.P. Bemberg).

The development of hemodialyzers capable of restoring a patient to a nearly normal condition led to the serious problem of continual access to the patient's blood. This was solved in 1960 by the introduction of the arteriovenous Silastic shunt of Scribner and Quinton. The development of a disposable coil artificial kidney by Kolff and Watschinger (1956) increased the popularity of hemodialysis. The successful do-it-yourself kidney such as the Kiil dialyzer contributed toward making hemodialysis more economical. Home dialysis was tried on acute cases in 1960 (Nose, 1961). However, the feasibility of successful, extended hemodialysis at home is attributed to Scribner and Merrill (1964). At this time many long-term hemodialysis centers and home dialysis training centers are active throughout the world.

Diffusion during dialysis



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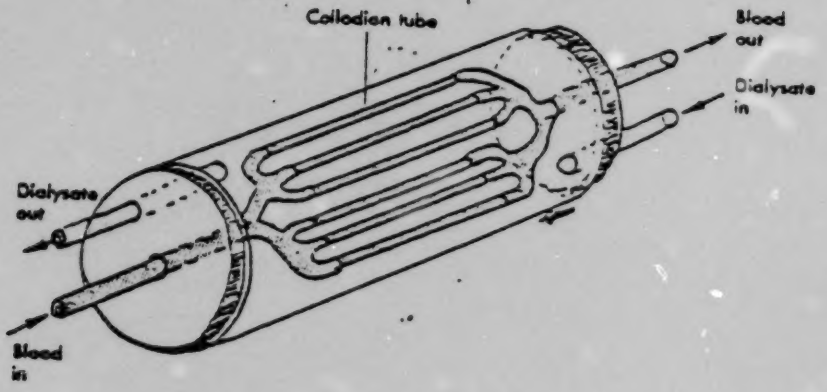
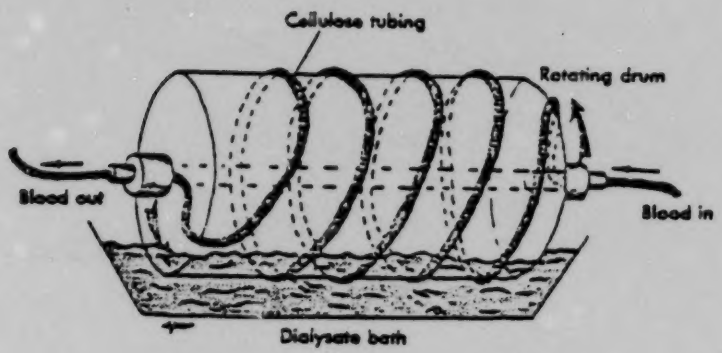
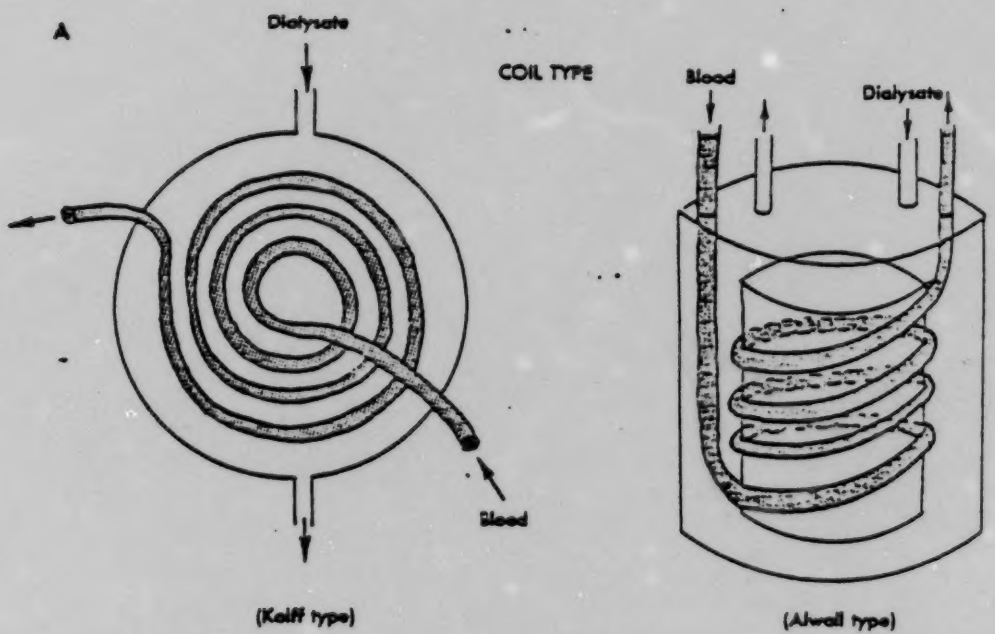
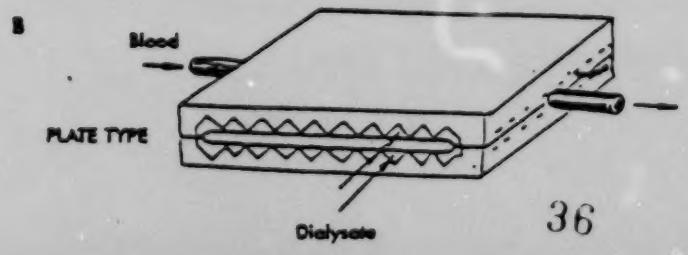
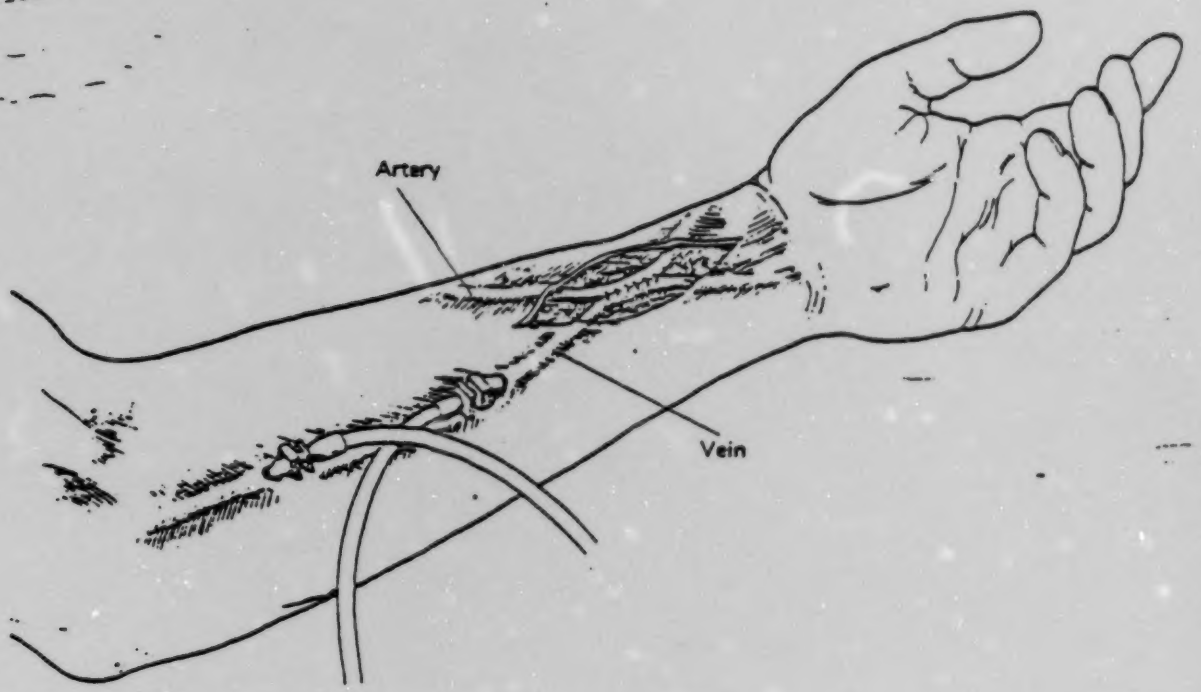

Collodion tube
Blood out
Dialysate in
Dialysate out
Blood in


Cellulose tubing
Rotating drum
Blood out
Blood in
Dialysate bath

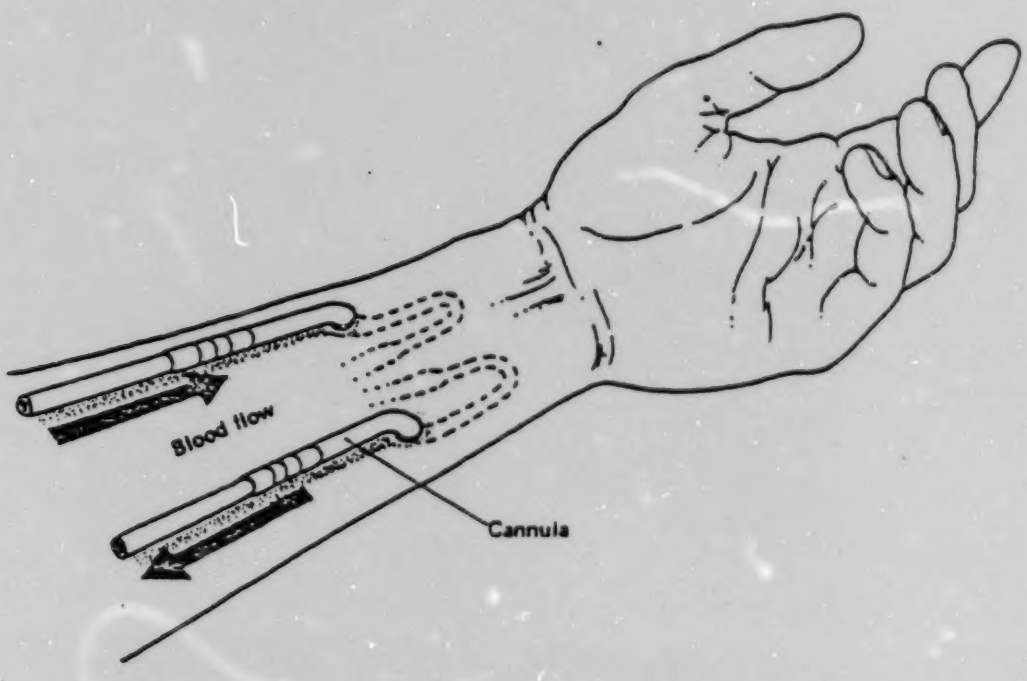

A
Dialysate
COIL TYPE
Blood
Dialysate
Blood
(Kolff type)
(Alwall type)


B
Blood
PLATE TYPE
Dialysate

Internal fistula



External shunt



MANAGEMENT OF END STAGE RENAL DISEASE

1. Size of Problem: 100-200 new patients with chronic renal failure in the Washington, D.C. Metropolitan Area per year or 50,000 per year nationally

2. Management

   a. Patient with GFR reduced below 20 ml./min. producing large amounts of urine (1500 ml./day or more).

      1) Protein restricted diet - 40-60 gm high biological value protein from eggs, beef, poultry, and fish
      2) Control of hypertension if required
      3) Control of edema by moderate salt restriction and careful use of diuretics
      4) Control of acidosis by use of $NaHCO_3$ supplement
      5) Prevention of hyperphospatemia and delaying development of 2^{o} hyperparathyroidism by use of phosphate binders such as aluminum hydroxide in G.I. tract

   b. Patient with GFR below 10 ml./min. producing 1500 ml. or more urine per day.

      1) Further protein restriction to 40 gms of high biological value proteins

   c. Patient with GFR below 10 ml./min. with developing oliguria

      1) Begin regular dialysis treatment
      2) Evaluate as a candidate for transplantation

3. Role of hemodialysis and peritoneal dialysis in management of chronic renal failure

   a. Dialysis provides the means of continued life until transplantation can be performed and provides the sole means of survival.

   b. Location of dialysis

      1) Limited care facility
      2) Satellite center
      3) Home dialysis
      4) Self dialysis at mobile or satellite unit

   c. Complications of dialysis

      1) Problems with access to circulation
      2) Infection
      3) Anemia - not corrected

4) Pericardial effusions
5) Subdural hematomas
6) Accelerated athrosclerosis
7) Emotional reactions to dialysis
8) Infertility
9) 2° hyperparathyroidism

4. Transplantation

a. Source of donors

1) Living related
2) Cadaver

b. Immunologic problems

1) Hyperacute rejection
2) Acute rejection
3) Chronic rejection
4) Infections from immunosuppression

c. Graft survival

1) Living related - 85% 2 year 15% per year decline
2) Cadaveric - 50% 2 year

Additional Reading Materials (optional)

1. Anderson, R.J., Gambertoglio, J.G. and Schrier, R.W., Clinical Use of Drugs in Renal Failure, Springfield, Charles C. Thomas, 1976.

2. Bennett, W., Singer, I. and Coggins, C.H., Guide Lines for Drug Therapy in Renal Failure, Ann. Int. Med. 86: 754-783, 1977.

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4. Gotch, F.A. and Krueger, K.K., Adequacy of Dialysis, Kidney International 7: Supplement 2, 1-266, January 1975.

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Adjustment to Dialysis - A Consumer Point of View

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An attempt will be made to describe the various stages/periods of experience with 7½ years of dialysis - seven of which have been at home, with considerable local and international travel. There appear to be three interconnected stages in this journey:

1. The initial shock and realization of kidney failure which included considerable and variable periods of fear, uncertainty, insecurity, anger, helplessness and determination to overcome -- directed in differing ways toward medical personnel, family, and self. This period also included adaptation to home dialysis, several medical complications, moving, and attempting to re-establish my professional status. This stage was one of fighting for survival.

2. The transition to acceptance included an interesting integrating process in establishing a physical, mental, and emotional sense of stability in the midst of uncertainty, i.e., the question of longevity and quality of life, rather than survival.

3. Acceptance and the future brings me to the past few years in which I no longer question the viability of future planning. This included an intellectual and experiential recognition of your mortality in addition to my own and the extraordinary excitement of utilizing to its fullest the meaning of birth: an opportunity of a lifetime.

Finally, I will try to suggest a variety of ways in which medical staff (doctors, nurses, technicians, social workers, and administrators) might approach the long term dialysis population by encouraging an increasing improvement in the quality of their lives. Issues concerning adjustment to dietary restrictions, reduced energy and strength, the question of sexual function and ability, social relationships, and one's self image will be discussed. Implicit in this entire presentation is the importance of the dialysis consumer's ability to accept responsibility for the quality of his long-term future, and the medical staff's commitment to both encouraging the acceptance of that commitment in addition to supporting and reinforcing it, once it has been made. In many cases, this requires a change of attitude on the part of the staff, because the issue is not survival or sickness: it is health and quality over the long term. The emphasis is not on what the dialysis consumer can't do, it is on what he can do and should try anew. This ought to be a dynamic situation where change is inevitable, not one of the status quo, or for that matter, equilibrium.

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Adjust to Dialysis

A Consumer's View

by John Newmann

Editor's Note: We are pleased to present excerpts from a presentation given by John Newmann at a conference on "Complete Management of the Long-Term Hemodialysis Patient." [Emory University, Atlanta, Georgia, March 1979] Although these remarks were addressed to health professionals attending the conference, we believe they are equally valuable for our readers.

I'm delighted to have been included in this seminar to share with you one person's experience with kidney failure and hemodialysis. As you will observe, my case is illustrative of some consumers of dialysis, and unfortunately, not yet representative of the majority. I do believe a substantial proportion of the long-term consumers of dialysis, perhaps 50%, could be living as I am, given a strong commitment by them and their medical staff toward improving the quality of their lives in addition to the obvious and necessary commitment to maintenance dialysis to insure survival.

My history of uremia began with a nephrectomy in 1960 of a congenitally small and infected kidney. Uric acid and creatinine levels rose slowly and steadily and a 1966 biopsy of the remaining kidney revealed scar tissue and infection. The remaining kidney ceased most function in September 1971, and I began hemodialysis in a satellite unit.

My wife and I, with two children ages 2 years and 6 months, chose home dialysis for the long-term because:

a. It was a financial necessity, given the absence of Medicare coverage in 1971;

b. I wanted responsibility and control over a medical procedure which could be fatal every time I required it;

c. We felt the home environment was more pleasant and safer than a clinic at that time, allowing us freedom of timing, a decent meal while dialyzing, visits with my children, family and friends, and separation from the risks of hepatitis, other people's mistakes, and sickness/depression of others on dialysis.

We had to wait six months before space was available for home training at the Kidney Center in Boston, where I began dialysis and have been monitored ever since.

Medical problems of long-term hemodialysis which I have encountered included:

1. Serum calicum/phosphorus instability which lasted 2½ years. I had a subtotal parathyroidectomy 15 months after beginning dialysis. It took over 15 months for any noticeable improvement in the serum calcium level or the bone pain accompanied by several rib fractures. In addition to continuous use of antacids and eventual vitamin D (DHT) therapy begun one year after the parathyroid surgery, I asked for and received permission to (a) de-ionize the water--even though at that time deionization was not commonly used and the New York City water chemistries did not require it; (b) begin one month of diathermy and massage treatments with hopes of encouraging a reversal of a very serious myopathy secondary to hyperparathyroidism and; (c) engage in light calisthenics. After four months of these activities I began to notice an improvement in muscle strength and a reduction in bone pain. The serum calcium/phosphorus ratio appeared to stabilize at normal levels.

2. Serum hepatitis was contracted from blood transfusions received at Peter Bent Brigham Hospital the day before the parathyroid surgery.

3. Hemolysis occurred in June 1975 when the dialysate was left out of the second bath due to negligence. This was simultaneously accompanied by severe pancreatitis for which there was no symptomatic history prior to the hemolysis.

4. In 1977 I developed a hiatal hernia and duodenal ulcer.

5. Within the last year my hematocrit, which has risen steadily over the years to 38%, has dropped to 26%. Imferon therapy has not affected any appreciable change. The increase in hematocrit occurred during a period of regular exercise, and the decrease occurred when I was not exercising regularly.

Those are most of the descriptive details of medical issues related to dialysis. I have an excellent fistula, no heart or circulatory problems, my chemistries are generally good, although I do tend to run high potassium and triglyceride levels. Generally my clinic visits every 2 or 3 months are very uneventful. I often use them as an opportunity to ask questions about possible research findings of promise in dialysis and transplantation.

The relevance to this seminar of my experience with chronic uremia, in my view, is the recognition of the inseparability of mind and body, their interconnection and interdependence. One clearly affects and is affected by the other. I've seen no convincing arguments or evidence that they are separate or independent--and therefore I strongly support an integrative, or holistic (if you will) approach to adjusting to hemodialysis.

(Continued on next page)

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Let me comment briefly on the three stages I've chosen to describe my own 7½ year experience: initial shock, transition to acceptance, and general acceptance. By *general acceptance*, I mean I no longer consider my life radically changed; I know what I must do to stay alive and I accept that. That does not mean my life is completely free from periods of depression, sadness and anger. The length of each stage is irrelevant, as each person brings with him his own history and mental, psychological, emotional, and physical characteristics; all of which are determinants of one's ability to change.

I. The initial shock and realization of kidney failure.

Initially my physical condition was extreme fatigue and weakness, which was very scary, disappointing and depressing.

I've always been active and athletic, with a very strong will. Particularly, in my 20's and early 30's, I believed I ought to be able to do most anything I set my mind to--in retrospect a very useful and constructive approach. I constantly asked as many questions as possible in an attempt to learn what was happening to me and what the prospects for the future might be. No one in my family had my blood type and I took a rather dim view of the survival and complication statistics of cadaver transplants.

Then, of course, there were the scores of questions about home vs. center dialysis, financing, dialysis vs. transplantation with an emphasis--by many doctors--that transplants which work return the patient to "a normal life." (This, in my opinion is one of the most unethical, irresponsible misinformation campaigns that some members of the medical profession have engaged in of late.) Fortunately, my doctors were more honest with me at the time, pointing out the many possible complications and long-term problems even with those transplants that "work." I was fortunate not to have had other serious medical problems along with chronic uremia, and my toleration of dialysis was quite good.

Family and friends generally were sympathetic without too much pity (although we got our share of that). And their support and praise for my wife's and my attitude was very helpful to me, and somewhat helpful to her. The family always was ready to help with dedication and love, primarily through assisting with care of our two children during the first six months before we began home dialysis and with financial assistance, as I didn't return to work for several months.

II. Transition to acceptance.

The second stage, transition to acceptance, occurred as I experienced several changes in my life, which initially appeared to be near destruction with the onset of dialysis. Over time, the scare of the dialysis procedure was reduced, my fistula developed well, and I became more familiar with the diet. I thought I was out of the woods.

Then came the bone pain, muscle weakness, the parathyroidectomy and the serum hepatitis. I made up my mind that I could no longer assume a trouble-free life on dialysis, given the occurrence every six months or more of a new complication. But I also noticed that the period in between these new challenges often resulted in getting accustomed to the changes and gradually feeling better--particularly physically, as benefits of my pushing myself to bike ride or swim were felt, which in turn helped my mental attitude. I feel it was this acceptance of the possibility of continual problems, rather than the expectation that eventually all would be better, which provided an additional mental/psychological perspective to live with the uncertain future.

It was also at this time when I began to feel and live with the beauty of being alive--having been aware of how close to death I was and could be with every treatment or unnecessary helping of lasagna. I began to cherish and love the blue sky and bright sunlight, in addition to the wind blowing against my face and through my hair. I found new excitement in a heavy rain and snow, and enjoyed being surrounded by them. The trees blooming, leaves turning color in the fall, and the beauty of a starlight night were all captivating. And the inexplicable variety of human love, thought, and expression by those on the bus or subway, among friends and family, those who write, act, and play music--brought and continue to bring tears and smiles of joy, in addition to tears of sadness and lumps in my throat when I realize I have no idea how much longer I may be amongst all this--nor do you for that matter.

III. Acceptance.

The third and present stage of my long-term dialysis journey is one in which I've returned to planning for the future, while trying to fully enjoy the present, and appreciating the past. Once I accepted the notion that I could have far greater control over my life than the doctors do, I experienced the benefits. I know how my body responds to various dialysis therapies. When traveling I decide how to run my treatments, which is difficult at times when attending new units.

In Retrospect...

What was left out of my treatment? In retrospect medical staff sensitivity and concern for the emotional and psychological problems beneath the surface. Who on the medical staff was helping us to deal constructively, not sympathetically, with tension, stress, anxiety, fear? No one. The problem was that my wife and I appeared so stable in their eyes, their and our assumption was that we were adjusting beautifully, and in comparison to others around us, we were.

It took considerable prodding on our part to see a psychologist or psychiatrist. We did on two occasions when we wanted to know if our approach to all of this was appropriate. He was so impressed with our attitudes that he, like friends and family, felt we were doing beautifully. We were not asked by him to stop and think about possible deep-seated issues, which may be festering away, such as what do you ultimately do with this problem, how do you feel about the effects this has on your relationship with each other, how do you deal with those moments of real fear, uncertainty, hopelessness, the "why me/us" questions?

I understand psychotherapeutic counseling is now more readily available. But, I wonder whether it ought to be required initially, particularly for the compliant patients, and certainly introduced to the borderline and non-compliant patients--to give all persons, spouses and family members a chance to accept or reject it--rather than waiting for them to muster up the considerable courage normally required to ask for it.

A second very important element, clearly the most important, left out of my initial experience with kidney failure, was being introduced to the variety of ways in which I could do something for myself and my condition, rather than concentrating on what I couldn't do (dietary restrictions) and what I had to do (dialysis, thrice weekly). You all have the common sense and experience in realizing that persons who take active responsibility for their lives, rather than passively assuming they have no control over their fate, do better--particularly on dialysis. My health and the quality of my life are simply too important to leave entirely in your hands. You can keep me alive in ways in which I can't, and I wouldn't be alive today if it weren't for you. I can't thank you enough for that. However, I was the principal in getting me back on the tennis court, in the swimming pool, climbing mountains, back to work, traveling and dialyzing from

Plattsburg, New York to Jakarta, Indonesia--and last but not least, enjoying the return to a normal sex life.

I would like to suggest to all of you that medical personnel can play an extraordinarily important role in assisting and suggesting a variety of ways in which your clients can take on responsibility for the quality of their lives. In the initial stage of dialysis, when death is a primary concern let me suggest a few approaches:

1. If you are asked statistics about survival, rejection, sexual function, employment, etc., in addition to stating what you know, you can do many dialysis consumers a service by suggesting that it is quite possible for each of them to be on the positive side of those statistics. You can describe persons you know who are doing beautifully on dialysis. I was told about a 30 year old professor of mathematics, on dialysis for 7 years at home--who cuts the lawn, plays with his kids, in addition to his professorial work. Once these people are used as illustrations, you can then relate how they have coped and overcome the problems of diet and other restrictions.

2. Secondly, if you want to try to assist in reducing the stress in your client's life, there is certainly no harm in introducing some form of relaxation therapy; initially in a clinic setting or on dialysis. I have found deep breathing and 10 or 15 minutes of simple meditation result in considerable physical and mental relaxation.

3. During this initial stage of becoming accustomed to dialysis, when physical strength is so reduced, I suggest each dialysis consumer be introduced to a modest program of exercise by a trained physical therapist after a careful review of the capabilities of each person. We all know that in addition to the debilitating effects of renal failure, the period following the onset of dialysis often is accompanied by both physical and psychological lethargy. The countless hours on dialysis and resting at home can cause additional atrophy of muscles, further weakening the body and negatively affecting the already severely challenged psyche.

Simple arm exercises, walking, climbing stairs, swimming, and more strenuous sports and calisthenics can be added where appropriate. Fortunately, beginning a daily modest exercise routine does show results rather quickly, which in many cases improves mental attitude and leads to additional return of previous physical capabilities.

4. Another suggestion in this holistic approach to long-term hemodialysis is encouraging a healthier diet. When I began dialysis and was introduced to all the dietary restrictions of liquid, potassium, sodium, calcium, phosphorus, protein, and sugars and fats, I was tempted to conclude my only safe, gastronomic delight was limited to salt free crackers. I later realized that almost anything could be consumed with moderation, but more importantly, the benefits of fresh produce far exceeded the preserved, pre-cooked, and even frozen varieties. I believe we have much to learn from objective exploration of the diets recommended by Adele Davis, in addition to the growing undercurrent of acceptance of Japanese, Chinese, and Indian nutritional traditions.

5. One additional way in which you can help people adjust to dialysis is to be ready to discuss openly and constructively their concerns about sex. When I heard about the high propensity of sexual dysfunction among dialysis patients, it was a self-fulfilling prophecy. No one suggested to me that it didn't have to be that way. When I speak to patient groups, I've found it useful to encourage them to literally take matters into their own hands in order to destroy the inappropriate myth of impotence. Once you re-experience your own physiological potential you can begin a variety of ways toward sustaining a healthy sex life with or without professional help.

Humor has been very important to me. We have to be able to laugh at ourselves a bit and not take every day or treatment so intensely serious. I once argue, (not terribly persuasively) with my employer that I deserved a 2-3% raise upon returning to work, given the additional time I spent at my desk in comparison to the others. He didn't quite understand until I pointed out one of the advantages of kidney failure was all the time one saved by not going to the bathroom every few hours.

In conclusion, I can't stress enough the importance of medical staff considering the whole person, his/her family and environment at the onset of chronic dialysis. Many doctors with financial interests and medical responsibility in satellite units are concerned with sickness and illness. Some doctors, nurses, technicians, social workers, psychologists, and government health planners are becoming more concerned about the *quality of life* we dialysis consumers lead, rather than just our survival. Let me encourage more dialysis consumers and medical staffs to join the *health* field, rather than limiting their interests to illness and survival.

Peritoneal Dialysis - As A Long-Term Treatment Modality

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National Kidney Foundation figures released in May, 1979, indicate that a total of 51,000 people in the United States are on some form of dialysis therapy. Hemodialysis has dominated the field with some 46,000 patients on center hemodialysis and 5,000 patients on home hemodialysis. In contrast, only about 300 patients were on chronic peritoneal dialysis. Why such a big discrepancy?

Peritoneal dialysis is not a new form of therapy. The first clinical paper describing peritoneal dialysis was published in 1923. This paper described the two major problems which inhibited the widespread use of peritoneal dialysis until relatively recently. Those problems were infection and access to the peritoneal cavity.

Commercially prepared sterile peritoneal dialysis solutions became available in 1959. This made peritoneal dialysis easier technically, but still left the original two problems - infection and access.

The development of the automated peritoneal dialysis machine in 1964 finally did reduce the infection rate, at least the infections caused by contaminating the tubing when changing bottles of dialysate. The machine automatically makes pure sterile water from tap water and mixes it in correct proportion with a special concentrated solution to produce dialysate. The machine then pumps the dialysate into the patient's peritoneal cavity, allows it to remain for a predetermined time period, then drains the dialysate - all automatically. This reduces the hazard of contamination which occurs when changing dialysate containers every hour, but still leaves the problem of access.

The next gigantic step forward was made by Dr. Henry Tenckhoff and his colleagues in 1968. They developed a silastic catheter with a dacron cuff which prevented the movement of bacteria down the outside of the catheter and into the peritoneum. This reduced the peritonitis rate and also provided a permanent access device.

The combination of machine and Tenckoff catheter form a safe system which is easy to operate, even at home by the patient. Why didn't patients clamor for peritoneal dialysis? The time requirement is one reason which kept peritoneal dialysis from serious competition with hemodialysis. Peritoneal dialysis requires about 40 hours a week while hemodialysis usually takes only 12-15 hours each week.

The latest chapter in the peritoneal dialysis story began in 1976 when Popovich, Moncrief and colleagues described the technique we now call continuous ambulatory peritoneal dialysis (CAPD). By lengthening the time the dialysate is left in the peritoneal cavity, it is possible to shorten the time the patient is actually occupied or immobilized by performing the dialysis procedure. Instead of performing hourly exchanges for 10-14 hours, 3 or 4 times a week, the patient always has dialysate in his peritoneal cavity. Changing the dialysate 4 times a day, seven days a week requires only a total of 2-3 hours per day and only 30-40 minutes at a time. When not actually infusing or draining dialysate, the patient is free.

Patients who qualify for this new method of dialysis must be carefully selected. Infection is again a problem when compared with machine peritoneal dialysis or hemodialysis. Protein is lost in the dialysate. On the other hand, CAPD does offer more mobility -- dialysis which does not require machinery or intravenous heparin can be done by the patient without help.

As of mid-September 1979, Medicare pays training fees, supply costs, and professional fees for CAPD, just as it does for hemodialysis. In addition, as a form of home dialysis, expenses are covered from the time training starts. Like other forms of home dialysis, it is considerably less expensive than center or hospital based dialysis, but probably slightly more expensive than home automated peritoneal dialysis. Training time required for CAPD is usually 10 to 15 working days.

These technical advances make peritoneal dialysis more competitive with hemodialysis. In the past few months there has indeed been a movement of patients to peritoneal dialysis - especially CAPD. Although many patients reach peritoneal dialysis because they are bad risks for hemodialysis, many are selection CAPD as a primary mode of therapy. CAPD does offer an unusual mobility and perhaps more opportunity to return to normal work and home activities.

Transplantation - New Directions and Patient Selection

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Many papers have been published concerning rehabilitation of amputees, cardiac patients, the elderly, the blind, the deaf, stoma patients, those with neurologic problems, and those with other diabilities. There are few publications concerning the rehabilitation of renal transplant recipients (4, 7, 9, 21). This is surprising, as transplantation has been available as treatment for end stage renal disease for more than two decades, and, currently, approximately 4000 patients per year in this country receive renal transplants. Various complications arise in these patients that either necessitate rehabilitation or that hamper their readjustment. In this paper we shall consider pre-existing problems that may persist after successful transplantation: those that hinder full rehabilitation postoperatively and the degree of rehabilitation that can be accomplished. Before we discuss these topics we shall briefly consider the various therapeutic measures that are necessary in renal transplantation.

THERAPUETIC MEASURES IN RENAL TRANSPLANTATION

Most people with kidney disease do not require dialysis or transplantation. They have a satisfactory reserve of functioning kidney tissue to maintain them in good or reasonably satisfactory health. However, when the disorders progress to the stage when chronic renal failure develops, patients will require treatment either with dialysis or transplantation to keep them alive. There are two types of dialysis: peritoneal dialysis, which requires the insertion of a cannula, through which fluids can be introduced into and removed from the peritoneal cavity; and hemodialysis, which entails the surgical construction of an arteriovenous shunt or fistula in the arm or leg, through which the patient is connected with a dialysis machine. Both procedures have risks of mortality and morbidity. Reoperation because of thrombosis, infection, or other complications involving the various access sites is quite common (16). The patient's life style is greatly limited by strict limitations of fluid intake, dietary restrictions, and the need for dialysis for periods of 6 to 8 hours, two or three times a week (16). In general, dialysis is reserved for patients who are not suitable for transplantation because of advanced age, other serious diseases, either physical or mental, or because of the presence of preformed cytotoxic antibodies which pose the risk of very rapid rejection of a transplanted kidney (16).

Most patients who undergo transplantation are treated with hemodialysis for weeks, months, or even years beforehand. Before or at the time of transplantation, some patients' diseased kidneys are removed and, also, splenectomy may be performed

as part of the immunosuppressive regimen. In the transplant operation, a healthy kidney, obtained from a cadaver or living donor, is inserted into the left or right iliac fossa. While most technical problems associated with the operation have been solved, difficulties are occasionally encountered with the vascular or ureteral reconstructions, which may contribute to the mortality and morbidity of the procedure.

Except in the case of transplantation between identical twins, a major concern in the postoperative period is the risk of immunologic rejection of the homograft. The prevention of rejection involves the use of two or more of the following immunosuppressive agents: Azathioprine (Imuran), Cyclophosphamide (Cytoxan), Corticosteroids (usually Prednisone or Methyl Prednisolone), or Antilymphocyte globulin (ALG) (16, 18, 20). During the first few postoperative weeks, large doses of these medications are administered, but as the danger of rejection diminishes, the quantities are reduced until maintenance levels are reached. The combination of drugs which is most frequently used in maintenance therapy is Azathioprine and Prednisone. Since rejection is an ongoing danger, treatment is continued indefinitely. Episodes of threatened rejection are treated with increased doses of corticosteroids, but if rejection is severe, the kidney may have to be removed and replaced with one or more subsequent homografts. In rare instances, patients have received as many as six kidney transplants.

In addition to the immunosuppressive agents, patients may also require a number of other medications. As hypertension is common, many patients require treatment with one or more antihypertensive drugs (16): hydrochlorothiazide, reserpine, hydralazine, methyldopa, guanethidine, furosemide, minoxidil, and propranalol. At times, recipients may require antibiotics to treat infections. They also require large doses of antacids during the period when they are taking large doses of corticosteroids to prevent possible peptic ulceration.

Postoperative convalescence requires weeks, or occasionally months, of hospitalization. After discharge from the hospital, the patient continues maintenance immunosuppressive therapy and is seen regularly in the outpatient clinic for re-examination and for routine hematologic, urinary, and radiographic studies (16).

PROBLEMS AFFECTING REHABILITATION

Persistence of Disorders Present Before Transplantation

Many of the harmful effects of chronic uremia disappear with restoration of normal renal function. However, some of the damage may be permanent and may require additional medical or surgical treatment and may present problems in rehabilitating the patients. These disorders include neuropathy, atherosclerotic cardiovascular disease, and osseous disorders that complicate chronic uremia, and the frequently associated secondary hyperparathyroidism.

Some of these problems are more common in diabetic patients who require transplantation. In one series the incidence of myocardial infarction was 11% in diabetic patients compared with 2% in nondiabetic recipients (10). Whereas no amputations were performed in a large number of nondiabetic patients, almost all of 132 diabetics had some peripheral vascular disease at the time of transplantation, and, subsequently, amputations of fingers, toes, or legs were necessary in 32 recipients (24%)(10). Persistent retinopathy and decreased visual acuity are also problems in diabetic patients.

Problems Arising After Transplantation

Renal transplantation is an imperfect form of treatment. A variety of complications occur which may impair or even completely prevent the patient's full rehabilitation.

Loss of renal function.

As will be indicated later in this paper, a substantial number of patients lose satisfactory function of their transplanted kidneys (16, 18). In most cases, this results from immunological rejection, which may be acute (occurring with the first few weeks or months) or chronic (occurring many months or years after transplantation). Less commonly, loss of renal function occurs because of technical problems or because of recurrence of the original disease that caused the patient's own kidneys to fail. Many recipients can be successfully rehabilitated by additional transplants, but if they are unsuitable candidates or such treatments prove unsuccessful, they will be returned to treatment with chronic dialysis and its associated restrictions and complications.

Infection

Infection is the most frequent complication of immunosuppression and is the most common cause of death in transplant recipients (16, 18). The weakening of the body's immune defenses by the immunosuppressive drugs makes patients susceptible to a wide variety of infections caused by bacteria, protozoa, viruses, or fungi. Infection and rejection are the major factors responsible for deaths, for rehospitalizations, and for loss of time from work or study or recreational activities.

Cardiovascular Problems

Athroma is a striking feature of untreated uremia (16), and cardiovascular complications are the leading cause of death in dialysis patients (11). As indicated earlier, persistence or progression of atheroma in the post transplant period may occur, and cardiovascular complications are the second leading cause of death in kidney transplant recipients(11).

Hypertension occurs at some stage in at least 50% of patients (16). This may require treatment with a sodium restricted diet and/or one or more antihypertensive drugs. Side effects of some drugs may hamper rehabilitation (see next page).

Genito-Urinary Complications

Approximately 10% of patients have problems involving the transplanted kidney or ureter, including urinary tract infections, ureteral stricture, ureteral calculus, hydronephrosis, compression of the ureter by a lymphocele, and urinary fistulas (19).

Sexual dysfunction occurs in 48% of men and 26% of women with chronic renal failure (6, 15). In many cases this improves after restoration of satisfactory renal function by transplantation, but it may persist or even develop de novo. Impotence is present in 22 to 43% of male kidney transplant recipients (1, 6, 17). Sexual problems in males or marked alterations of physical appearance in females, resulting from chronic corticosteroid therapy, have caused the break up of a number of marriages of transplant patients (15).

Musculoskeletal Problems

Thirty eight percent of a group of patients studied had avascular bone necrosis, synovitis, arthralgia, or diffuse musculoskeletal pain (3), most probably caused by chronic corticosteroid therapy. Other problems caused by this treatment include vertebral collapse, pathologic fractures, and myopathy (16).

Gastro-intestinal Complications

Problems that are encountered include bleeding or perforation of a peptic ulcer, acute colitis or perforation of the colon, and pancreatitis (16).

Cancer

An increased incidence of certain types of malignancy is seen in transplant patients (14, 16). The most frequent are cancers of the skin, lymphomas, and in situ carcinomas of the cervix of the uterus. These will require treatment with surgery, radiotherapy, chemotherapy, or various combinations of these treatments.

Psychiatric Problems

Many patients with chronic renal failure develop psychiatric problems (1,12, 15). Fear, depression, and anxiety are understandable reactions to the knowledge that the patient has a dangerous and, possibly, fatal illness. These feelings may be aggravated by conflict over dependency on other family members and envy of their health. Distress about financial problems, inability to function as the family breadwinner, and sexual dysfunction also commonly accompany chronic renal failure. At least 13% of patients with psychiatric problems threaten suicide at some stage (15).

After successful transplantation many of these problems are resolved, but some persist and other patients develop psychiatric problems for the first time. Thirty two percent of recipients have psychiatric symptoms (12, 15). Depression and anxiety are the most common and often appear in response to medical complications, such as infection or threatened rejection. An organic psychosis may result from several causes, including large doses of steroids, infectious complications, and poor renal function. The antihypertensive drugs may also cause psychological side effects. The patient often has adjustment difficulties, as a successful operation may convert him from a dependent status to one in which he must once again become independent and cope with life's problems. Occasional recipients who are unable to adjust may manifest suicidal tendencies.

Side Effects of Medications

The numerous medications that recipients have to take (immunosuppressive agents, antihypertensive drugs, antacids, and antibiotics) may have deleterious side effects which may interfere with the patient's rehabilitation (12, 15, 16). On a long term basis, most problems result from chronic corticosteroid therapy and, to a much lesser extent, from the antihypertensive drugs. Complications caused by the corticosteroids include: obesity; moon facies, acne, hirsutes, and other features of Cushing's syndrome; hypertension; osteoporosis; avascular necrosis of bone; diabetes mellitus; stunting of growth in children; possibly causing or aggravating existing peptic ulceration with bleeding or perforation; fatty infiltration of the liver; psychiatric disorders; cataracts; pancreatitis; and infection and disruption of operative incisions (12, 15 16). Therapy with antihypertensive drugs may cause postural hypotension, depression and other psychic disturbances, lassitude, weakness, loss of libido, and impotence (12, 15).

REHABILITATION

Average survival figures of large numbers of patients from all over the world indicate that between 61 and 78% of recipients of kidneys from related living donors are alive 5 years after transplantation, while with cadaver kidneys the figure is 42 - 51%. Functional survival of the kidney graft at 5 years is 45 - 66% in recipients of living donor kidneys, and 29 - 35% in recipients of cadaver organs (2).

At first sight it may appear that kidney transplant recipients have little opportunity for rehabilitation as they have to make repeated follow up visits to the hospital for monitoring of the function of their kidneys and other organs, and, at times, may require rehospitalization(s) for treatment of complications. Nevertheless, considering the gravity of the illnesses for which transplantation is performed, a remarkably high percentage of patients are rehabilitated. Between 62 and 90% of patients, who survive with a functioning graft, are rehabilitated, the lower figure representing patients with short term follow up

(at least 6 months) and the greater figure those who have been followed for up to 10½ years (7, 9). They are able to return to full-time employment, housekeeping activities, or school programs. Almost all of these patients achieve rehabilitation within 12 months after transplantation. However, one third of these patients function at a lower level than before their illness. A significant number of recipients, who had physically strenuous jobs before their illness, acquire sedatory jobs after transplantation, since many physicians advise their patients to avoid heavy work, especially weight lifting (7). This advice means that some patients must make career changes. Patients who have undergone a second kidney transplant have the same degree of rehabilitation as those who have had only one transplant (21).

Successful rehabilitation is much more frequent after transplantation, than after dialysis. In a series of 192 long-term survivors that were studied, only 18% were rehabilitated while on dialysis, while after transplantation the figure rose to 73% (5).

During the end stage of renal disease, female patients often complain of loss of libido, anovulatory vaginal bleeding, or amenorrhea, while males complain of loss of libido and impotence (8, 13). A gratifying feature of rehabilitation after successful renal transplantation is that sexual function returns to normal in many patients and affords them the opportunity to become parents if they so desire. In a group of 538 of our patients, parenthood was theoretically possible in 343, and 36 male and 24 female recipients have already achieved parenthood (8). Because of the uncertain life expectancy following renal transplantation, patients are counseled regarding family planning. It is made clear to them that they may not live long enough to rear their children to adulthood and may leave their spouses with the problem of rearing their children. Pregnant female transplant patients are also cautioned about increased risks to themselves (toxemia, rejection) and their offspring (mainly complications of prematurity)(8, 13).

CONCLUSIONS

Renal transplantation has saved the lives of large numbers of people suffering from a grave illness, chronic renal failure. It is not a perfect form of treatment, as complications and fatalities do occur. Nevertheless, a high proportion of patients can be restored to useful and productive roles in their families and in society. Physicians, nurses, rehabilitation counselors, and others play an important role in facilitating the patients' physical and mental adjustments. If necessary, some patients may require retraining or further education to equip them for less strenuous occupations than those they held before renal failure incapacitated them.

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Vocational Potential of ESRD Clients

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INTRODUCTION

There are many variables that could interfere with successful vocational rehabilitation and employment for the End Stage Renal Diseased patient. Some of the variables include the medical status of the patient, the psychological aspect, particularly the impact it has on both the patient and family members, and the patient's attitude and motivitation to return to work. Because dialysis takes an extensive amount of time from the patient's normal routine, including time to reach the center, time spend during dialysis, and a fair amount of time spent for recovery, the patient's vocational interests and work values may decrease. The lack of motivation and interest sometimes leads to lower vocational productivity, interference with educational plans, and in some instances, unemployment.

Beginning January, 1978, a study was conducted at Emory University Center for Rehabilitation Medicine to obtain quantitative data on the characteristics of ESRD patients. This segment of the study focuses on the vocational characteristics most significant in long-term dialysis and kidney transplant patients. The end product of this study, which will conclude in 1981, shall be to identify types of vocational problems, barriers, or characteristics according to the frequency and intensity as reported by the long-term dialysis and transplant patients, and as compared to the shorter-term patients. In 1979, we gathered data on 32 new patients (21 males and 11 females, 10 blacks and 22 whites). In addition to the 32 new patients, 16 patients from 1978 returned for a follow up evaluation. (Thus, the total number of subjects evaluated to date in 1979 is 48.) We described the long-term patients as those who have remained on dialysis or transplantation for four (4) or more years. The shorter-term patients (the comparison group) are those who have been on dialysis or transplantation less than four years.

PROCEDURE

In this study, the Hester Evaluation System was employed to measure cognitive-motor functioning of ESRD patients. The H.E.S. was developed in 1976, by Edward J. Hester Ph.D, an industrial psychologist who heads the Chicago Goodwill's research and program development staff. The system is psychometric in nature and it taps upon independent ability factors that are not usually measured by other systems. The system is a unique and comprehensive method of assessing vocational abilities.

It then relates them to specific jobs in a broad range of industries or occupational categories. The H.E.S. has over 1500 jobs on file that are derived from the Dictionary of Occupational Titles (D.O.T.) which is a two-volume set published by the U.S. Department of Labor, listing over 22,000 jobs.

Since this part of the study was to speak to the vocational characteristics, a subset of the system was administered. The entire test battery consists of 26 tests measuring some 28 ability factors. For our purposes, only eleven of these tests were given which basically measured perception, coordination, dexterity, reaction time, and steadiness requiring use of either the dominant or both hands.

INSTRUMENTATION

The eleven subtests selected to measure cognitive-motor skills are described below and hence forth will be referred to as Hester #1 through 11.

Hester #1 (Fine Finger Dexterity) - This factor involves the use of skillful, controlled finger movements to manipulate tiny objects through a small space. The Purdue pegborad is used where the patient has to place as many pegs as possible in the holes with the dominant hand, non-dominant, and both. It involves a 3-trial period within 30 seconds time span each. The patient's score is the number of pegs placed in the holes.

Hester #2 (Wrist-Finger Speed) - This task requires the patient to tap on a metal plate with a metal tip stylus for a 30-second time period. It measures one's ability to make rapid vertical movements of the wrist and hand. The number of taps made equals the patient's score.

Hester #3 (Arm-Hand Steadiness) - This factor measures the person's ability to hold his/her hand and arm in a specified position. (There are nine holes going from left to right with decreasing diameters mounted on a plate measuring 5-½" horizontally and 4" vertically and standing at a 45° angle.) Beginning with the second largest hole and working to the right, the patient is instructed to hold the metal tip stylus inside the holes without arm support and try not to touch the sides or back of each hole. The patient is timed for 15 seconds each for 4 holes and his score equals the number of electronically recorded errors.

Hester #4 (Manual Dexterity) - This task requires the use of the Minnesota Rate of Manipulation Dexterity test which includes 58 large pegs having two colors (red on one side and black on the other). It measures one's ability to make gross, rapid, and skillful arm-hand movements to turn the pegs. The score is the number of seconds it took the patient to turn all 58 pegs.

Hester #5 (Two-Arm Coordination) - This measure requires simultaneous and coordinated movements of the whole arm to trace a star with a metal tip stylus. It is performed by having the patient sit in front of the star with both hands manipulating two handles by sliding, gliding, and moving the handles apart or together around the star. The patient is instructed to stay within the blackened area of the star and avoid touching the area outside of the star. This measure takes into consideration both time and accuracy.

Hester #6 (Two-Hand Coordination) - This test employs the Etch-A-Sketch where the patient has to simultaneously coordinate two dials, one for vertical movements, the other for horizontal, by using both hands to move through a maze. The object of the task is to move through the maze without touching the sides. This measure is recorded with emphasis on both time and accuracy.

Hester #7 (Aiming) - This test is performed by using the same instrument used for the arm-hand steadiness ability. It involves the ability to move one's hand to a precise stationary target, in this case, moving a metal tip stylus through all nine holes from left to right without touching the sides. This measure also emphasizes the importance of time and accuracy.

Hester #8 (Reaction Time) - This factor relates to one's ability to respond quickly to a visual cue by depressing a key as soon as a color is flashed. The score is electronically recorded in hundredths of a second.

Hester #9 (Visual-Motor Reversal) - This ability factor requires one to reverse his/her visual field of reference and retain motor control. It relates to one's overall flexibility, requiring the ability to trace around a five-point star by way of a mirror. Here, again, emphasis is being placed on time and accuracy. It relates to one's ability to learn new tasks.

Hester #10 (Response-Orientation) - The instrument used to measure reaction time also yields one's response orientation ability. This factor is related to one's ability to respond quickly and accurately among three visual stimuli. The difference here is that the patient now must choose between 3 colors and 3 keys associated with the colors. This measure is electronically recorded in hundredths of a second.

Hester #11 (Fine-Perceptual Motor Coordination) - This aspect relates to eye-hand coordination and it tests one's speed and accuracy to follow or track a moving band of light around a stationary triangle. The person must stand in front of the machine and hold a stylus in his/her dominant hand, placing the sensitive tip directly over the spot of light. The greater amount of time the stylus is held over the light, the higher the score will be. The score is electronically recorded to the nearest one-tenth of a second after 30 seconds are given to complete the test. Visual impairment would create a problem when performing this task.

RESULTS: PATTERNS OF CORRELATIONS

Hester's scoring system uses a 6-point ordinal scale with 1.0 representing the lowest score obtainable and the lower 2.28% of the population, while a score of 6.0 represented the highest score obtainable and the upper 2.28% of the population. Hester's average equals 3.5 with scores of 2.0 and 3.0 falling one and two

standard deviations below the mean; the scores of 4.0 and 5.0 falling one and two standard deviations above the mean as shown in Fig. 1.

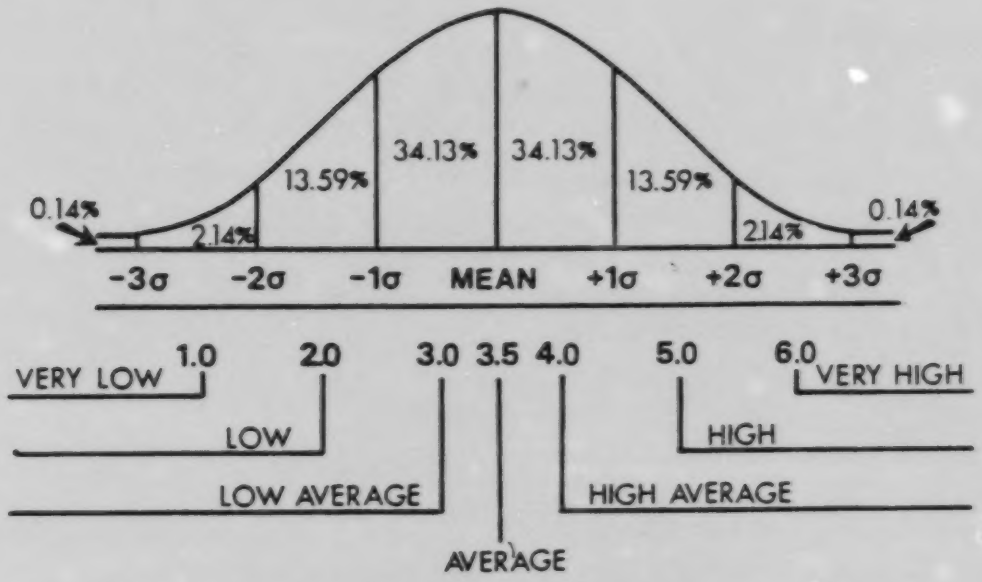

Fig. 1 Hester Scoring System Converted To A Normal Distribution

After converting the raw data into Hester's scale scores, comparisons were made to note whether or not ESRD patients performed at a lower or higher level of performance than Hester's population. A frequency distribution was established. It was suggested that ESRD patients had scored on most of the variables at higher levels of performance than Hester's "normal" population with the exception of three measures. The three measures that did not have an average of 3.5 or better were Finger Dexterity, Two-Hand Coordination, and Fine-Perceptual Motor Coordination skills. There was only one measure that came closest to Hester's average of 3.5. That variable was Reaction-Time (see Table 1).

A bi-modal distribution was found on Hester variable #6 (Two-Hand Coordination) that reflected two different groups of patients' performances which contributed to the slightly below average level. F-tests of Hester scores with sex showed larger variation among males than females on two variables. These variables measured Aiming and Response Orientation. Correlations with sex suggested that males had a tendency to score higher than females. Significant variance was found among whites and blacks on Hester variable #7 (Aiming). Whites scored significantly higher than blacks.

Those patients who spent less than twelve hours of inactivity scored significantly higher on Hester variables #1 (Finger Dexterity), #7 (Aiming) and #10 (Response Orientation) than those patients who reported more than twelve hours of inactivity.

The Hollingswood Two-Factor Index of Socioeconomic Status was used to determine the SES (socioeconomic status) scale and patients' educational levels. The scale has 5 categories based on educational levels and major type of employment and/or occupational classifications. Both factors are weighted with occupation being weighted more heavily. From these factors a socioeconomic status score is derived. Five scores are possible. For this analysis, high and low were derived from dividing the 5 groups into two groups using the median to define high and low.

The educational levels were derived similarly where a median scale score divided the high and low groups. The low educational levels comprised the group of patients whose educational achievements were 0-6 grades through high school, while the higher educational levels were those of patients who had achieved beyond high school education.

The lower socioeconomic status group showed more variation than the higher socioeconomic group on Hester variables #5 (Two-hand Coordination), #7 (Aiming), and #9 (Visual-Motor Reversal). The higher socioeconomic group had a tendency to score higher on those variables than the lower socioeconomic group. Some reasons for this significant difference could be due to the fact that the higher socioeconomic group was found to be more stabilized to the disease, more likely to be employed, spent 12 hours or less of inactivity, had achieved higher educational levels, made precise movements, overall flexibility to learn new tasks, and more coordination.

The unmarried group showed larger variations than the married group on variables measuring #4 (Manual Dexterity), #5 (Two-Hand Coordination), #7 (Aiming), and #2 (Wrist-Finger Speed). Further studies are warranted, but at this point in our research, we have not investigated other characteristics among these groups that perhaps contribute to the variations.

Long-term patients. When comparing long-term ESRD patients' performance to Hester's population, long-term ESRD patients scored significantly higher than Hester's normal group on all but two variables. These two variables were Finger Dexterity and Fine-Perceptual Motor Coordination. Reaction Time was the only variable on which both groups scored similarly (see Table 2).

Four (20%) of the long-term dialysis patients evaluated had experienced a discontinuation of employment or housework, and eight (40%) had experienced a decreased in employment or housework. The remaining eight (40%) long-term patients had the same or better status in employment, housework, or school as they had in their premorbid state or before dialysis. As our sample size increases, it will be important to examine the factors associated with these varying changes in vocational status. Data obtained thus far from long-term patients suggest that discontinuation of employment/housework occurred because of pronounced medical complications in three cases; and the fourth patient had a low educational and I.Q. level and seemed to have little motivation to be employed. Of the eight long-term patients who reported a decrease in amount of employment or housework, pronounced medical complications were present for six, and one older patient attributed her decreased housework to her age. These subjects were generally satisfied, however, with their level of activity in relation to their current medical status. For example, two men found volunteer activities very rewarding, and one preferred volunteer work (e.g. community planning and group leadership) because he said he never knew how he would be feeling from one day to the next. One subject claimed to be seeking full-time employment, but maintained that job discrimination definitely exists for renal patients. Interestingly, this same subject when follow-up in 1979, continues to say that he is seeking full-time employment and that job discrimination is a problem.

Employment was prevalent among longer-term patients, and they reported being more satisfied with leisure-time activities than the shorter-term group. Longer-term patients were also likely to be independent in transportation, ambulation, and mobility. This independence suggests stability and ajustment to dialysis, which in turn enabled patients to perceive their situation positively. Comparison of the longer-term and shorter-term groups revealed higher performance scores on three tests among the longer-term patients. Although both groups scored higher than Hester's populations, the longer-term patients scored significantly higher on tests measuring Arm-Hand Steadiness, Two-Arm Coordination, and Two-Hand Coordination (see Table 3). Their high performance on these cognitive-motor tests may be related to the fact that longer-term patients reported fewer medical complications that could have interfered with or hindered their performance outcome. Higher performance by longer-term patients on cognitive-motor functioning may stem from their acceptance of the disease, their anticipation of a continuous employment stuatus, better vision, and greater coordination of hands and whole upper extremities, as compared to shorter-term patients. Unlike the long-term patients, the short-term patients have not given much thought to a long and permanent employment status. With the time involved in dialysis, adjusting to the disease, and dependency on a machine, they are more likely to concentrate on survival.

Transplant Patients. Because only eight transplant patients have been evaluated thus far in the project, our discussion of the status of this group is very brief in this report. In spite of discouraging reports on a decrease in transplantation, we anticipate a significantly larger sample of transplant patients during the third year of the study, due to the impressive recent increase in available kidneys in Georgia.

We have evaluated five men and three women who have received transplants. Three of the men are fully employed, one is waiting for his doctor's permission to return to work, and one is retired. Two women are employed full-time and the other woman hopes to return soon to secretarial work if her rejection signs disappear. There seems to be no quesiton that these patients prefer their transplant status to their dialysis status.

Follow Up of Patients Evaluated in 1978. Five of the 35 dialysis patients evaluated in 1978 have subsequently received transplants. One of these subjects has experienced debilitating complications, due to the anti-rejection drugs required. He continues to work, however, as much as possible. Two patients have returned to work or school, one patient continues to receive disability payments, and one patient is actively seeking employment. One patient described his post-transplant status as markedly improved, both physically and psychologically. However, he remained very skeptical about his employment prospects, believing that employers reject renal patients who are on dialysis and that this rejection also extends to transplant patients.

Follow up patients, as a group, scored significantly better in 1979 than in 1978 on three of the Hester vocational evaluation tests: Manual Dexterity, Reaction Time, and Visual-Motor Reversal. This improvement, however, may be due to familiarity with these tests and a more relaxed attitude at the time of the follow up evaluation. On Hester variable #3 (Arm-Hand Steadiness), the follow up patients as a group scored significantly lower in 1979. The patients' performance did not cause this change, but rather a change in the testing situation. For various reasons, some patients sat to do the test in the 1978 study, but stood while performing the test in the 1979 study. For the remaining ten Hester tests, there were no significant differences between patients' scores in 1978, and their follow up scores in 1979.

DISCUSSION

Results of the cognitive-motor testing indicate that ESRD patients have enough basic skills to pursue an occupation. However, they may fear the deprivation of Social Security benefits if they were to become gainfully employed. If more dialysis and transplant patients are to pursue employment, financial and personal satisfaction incentives must equal or exceed the bendfits they are now receiving in their unemployed status.

The Rehabilitation Act of 1973 (PL-603) which provides financial coverage for the medical care of ESRD patients strongly supports center dialysis which requires a large amount of time. The time involvement in going to a center to dialyze was considered by some patients as full-time work in itself, which led to decreased vocational interests, altered educational plans, and, in some instances, unemployment. It is possible that the passage of HR-8423 will encourage more patients to train for home dialysis, which should subsequently enhance the employment outlook for dialysis patients.

It is our belief that patient educational programs could assist in the return of lower socioeconomic persons to gainful employment. Dialysis and transplant patients experience fatigue more readily than do persons who do not have kidney failure, and it may be difficult for such patients to function well in a setting which requires them to be on their feet. Education for a sedentary-type occupation and/or the possibility of a shared job (i.e., four hours worked by one individual and four hours worked by another individual) might be very effective in returning kidney dialysis and transplant patients to gainful employment.

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TABLE I

FREQUENCY DISTRIBUTION OF HESTER SCORES

Name of Test	N	$\bar{X}$
Finger Dexterity	53	2.94**
Wrist-Finger Speed	53	4.36
Arm-Hand Steadiness	53	4.50
Manual Dexterity	53	4.09
Two-Arm Coordination	53	5.00
Two-Hand Coordination	53	3.40
Aiming	53	5.56
Reaction Time	50	3.50***
Visual-Motor Reversal	53	4.09
Response Orientation	50	4.68
Fine-Perceptual Motor Coordination	52	2.38**

**Below H.E.S. Average
***H.E.S. Average = 3.50

TABLE 2

HESTER MEAN SCORES: LONG-TERM PATIENTS

Name of Test	N	$\bar{X}$
Finger Dexterity	17	3.11**
Wrist-Finger Speed	17	4.41
Arm-Hand Steadiness	17	5.41
Manual Dexterity	17	4.70
Two-Arm Coordination	17	5.47
Two-Hand Coordination	17	4.23
Aiming	17	5.82
Reaction Time	16	3.56*
Visual Motor Reversal	17	4.35
Response Orientation	16	4.93
Fine-Perceptual Motor Coordination	16	2.50**

*Hester's Average Performance

TABLE 3

COMPARISON OF SHORT-TERM (N_1) AND LONG-TERM (N_2) PATIENTS

Test	N_1	N_2	$\bar{X}_1$	$\bar{X}_2$	S_1	S_2	P-Values
Finger Dexterity	36	17	2.86	3.11	1.09	0.69	0.30
Wrist-Finger Speed	36	17	4.33	4.41	1.17	0.87	0.80
Arm-Hand Steadiness	36	17	4.08	5.41	1.92	1.00	0.01*
Manual Dexterity	36	17	3.80	4.70	1.80	1.10	0.06
Two-Arm Coordination	36	17	4.78	5.47	1.05	0.51	0.01*
Two-Hand Coordination	36	17	3.00	4.23	1.91	1.40	0.02*
Aiming	36	17	5.44	5.82	1.08	0.40	0.16
Reaction Time	34	16	3.44	3.56	0.96	0.72	0.60
Visual-Motor Reversal	36	17	3.97	4.35	2.04	1.80	0.50
Response Orientation	34	16	4.55	4.93	1.26	0.25	0.24
Fine-Perceptual Motor Coordination	36	16	2.33	2.50	0.99	0.51	0.52

*Mean of N_1 is significantly different ($P _ 0.05$) from Mean of N_2

A Comparison of Long-Term and Short-Term Hemodialysis Clients

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A pilot study, "Renal Rehabilitation Success Determination," was initiated in 1977 by Dr. Samuel Chyatte to intensively explore the medical and rehabilitation status of a sample of the renal population in the Atlanta metropolitan area.

As an outgrowth of that pilot study, a three-year project was developed in order to focus on the characteristics and needs of long-term ESRD patients, that is, patients whose treatment began four or more years ago as compared to the characteristics of short-term ESRD patients.

This project focuses not only on the medical and rehabilitation status of patients (as the 1977 pilot study did), but also on psychosocial, vocational, and demographic characteristics of patients. We are continuing to study the renal population of the Atlanta Standard Metropolitan Statistical Area (SMSA), identified by patients' use of the major dialysis centers in the Atlanta SMSA. The data cannot be generalized to the entire dialysis population in the United States. Rather, the project design calls for an extensive battery of data to be collected from 150 ESRD patients in the Atlanta SMSA over a three-year period, January 1, 1978 - December 31, 1980. Three hours or more of the patient's time is required to complete this battery of evaluations.

An additional component of the present study is the follow up of patients entered into the study in the first two years, 1978 and 1979. Patients entered in 1978, are to be reevaluated in 1979 and 1980. Thus, data will be collected at three points in time for one group and at two points in time for a second group, allowing longitudinal analysis of patient outcomes in vocational, psychosocial, and medical/rehabilitation areas. A critical need for follow up data on dialysis patients has been noted.

Measuring Instruments: The following evaluations are being employed in this study:

(1) A semi-structured interview requesting demographic information and the patient's perception of his/her current medical, vocational, and family situation;

(2) Evaluation of muscle strength, range of motion, and nerve conduction velocity;

(3) A series of written psychological tests tapping I.Q., self-rated depression, self-rated anxiety, mood state, characteristic emotional style, social adjustment, and family environment;

(4) Cognitive-motor skills which have implications for vocational abilities, using the Hester Evaluation System.

During 1978, data were collected from 37 end stage renal disease (ESRD) patients. It should be noted that dialysis patients represent a study population which is susceptible to sudden changes in physical status, for example, sudden debilitating changes in blood pressure. For this reason, subjects may cancel appointments or activities which they had otherwise planned to carry out. In both 1978 and 1979, therefore, cancellation and rescheduling of appointments has been frequent.

In all cases, we determine the reason for a cancelled appointment, and we attempt to reschedule another appointment. Taxi service is furnished for patients who request it; reimbursement for mileage is offered to those who drive themselves. Lunch is provided for the patient and family, if present, at the Emory Rehabilitation Center. These procedures have produced a total sample of 32 subjects being entered into the study during 1979. Additionally, 16 patients from 1978 have returned for a follow up evaluation in 1979. (Thus, the total number of subjects evaluated to date in 1979 is 48.)

In addition to 17 long-term dialysis patients, we have also evaluated a total of 36 patients who have been on dialysis for less than four years.

Comparison of data obtained from long-term and short-term dialysis patients indicates the following statistically significant differences between the two groups:

1. Dialysis site: Long term dialysis patients are more likely than short-term patients to dialyze at home than in a center. It should be noted that home dialysis requires the assistance of a willing partner and hence implies the availability of pronounced familial or "significant other" support to the patient. On the other hand, we have observed strong social support systems for some center dialysis patients as well. For example, a husband or wife who goes with the Spouse to the dialysis center three times a week and who repeatedly speaks of "our treatment," indicating strong identification with the patient's situation. Thus, it is not necessarily true that home dialysis patients have greater social support than center dialysis patients.

2. Medical status: Long-term dialysis patients are less likely than short-term dialysis patients to report visual impairment.

   Long-term dialysis patients report lower average weight gain between dialysis (edema) than do short-term patients, indicating more attention to following recommended diet and fluid restrictions.

   The most recent lab measures of inorganic serum phosphate and blood urea nitrogen were significantly lower for long-term dialysis patients than for short-term dialysis patients. Similarly, Foster and others in 1973, reported a relationship between a low blood urea nitrogen level and long-term survival on hemodialysis.

3. Self-rated satisfaction: Long-term dialysis patients are significantly more satisfied with the time they spend in hobbies and spare-time activities than are short-term dialysis patients.

In addition to the statistically significant differences reported, we can provide the following descriptive information about the long-term patients in our sample to date:

The most frequently observed primary diagnosis for long-term patients was pylelonephritis. There was no secondary diagnosis for half of these patients. Another 25% had more than one additional problem.

Long-term patients were aware of their diet and fluid limitations; the average fluid limit for this group was 28 ounces a day.

Complications most likely to be named by long-term patients were severe fatigue, moderate or severe neuropathy, moderate cramping, and moderate edema. Average body chemistry values were obtained for the long-term group. All values are within the desired range for dialysis patients with the exception of serum carbon dioxide content, which is lower than the desired value, and serum creatinine, which is higher than the desired value.

Manual muscle strength scores, range of motion scores, timed mobility, and intact distal sensation scores were normal for the majority of long-term patients. Half of the long-term patients, however, reported minor fatigue and half reported moderate fatigue. Three (17.6%) patients did not achieve 30 pounds of grip strength ($\bar{x}$ = 56.2 pounds).

In order to obtain a measure of patients' satisfaction with their current status on various dimensions, important in rehabilitation, a 100-point self-rating scale was used. From their own perspective, patients rated their current satisfaction, compared to when they were well, with their medical situation, working or homemaking situation, sexual life, family relationships, leisure activities, social life, financial status, self-image, mobility, manual dexterity, self-care, ability to travel, and appetite. Patients marked a point on a 100 millimeter line to describe their feelings on these thirteen dimensions, with 100 equal to "the same or more satisfying" and 0 equal to "not at all satisfying." Average satisfaction ratings for long-term patients are presented in Table I.

TABLE I

MEAN SATISFACTION RATINGS OBTAINED FOR LONG-TERM DIALYSIS PATIENTS

Family Relationships	82.1
Self-care	76.1
Leisure activities	73.4
Self-image	71.8
Social life	71.8
Manual dexterity	68.4
Appetite	67.0
Mobility	62.0
Sexual life	58.9
Medical situation	52.5
Financial status	48.5
Working/homemaking situation	43.4
Ability to travel	39.1

Long-term patients were most dissatisfied with their ability to travel, their working or homemaking situation, and their financial status. On the other hand, family relationships, self-care, leisure activities (time spent in hobbies and spare-time activities), social life, and self-image were quite satisfying to these patients.

Similar questionnaires were completed by spouses of married patients or by significant others if not married, and also by one of our three interviewers to evaluate his/her perceptions of patients satisfaction.

TABLE II

Correlation of Spouse and Patient

Self-rated Satisfaction (N = 29 Couples)

Satisfaction	Correlation*
Medical Situation	.42
Work	.55
Sexual Life	.77
Family Relationships	.70
Leisure Activity	.37
Social Life	.42
Financial Status	.40
Self-Image	.40
Mobility	.67
Manual Dexterity	.68
Self-Care	.56
Ability to Travel	.43
Appetite	.47

*Pearson Product Moment Correlation

TABLE III

Correlation of Interviewer and

Patient Self-Rated Satisfaction (N=47)

Satisfaction	Correlation
Medical Situation	.19 n.s.
Work	.43
Sexual Life	.53
Family Relationships	.81
Leisure Activity	.42
Social Life	.48
Financial Status	.35
Self-Image	.52
Mobility	.59
Manual Dexterity	.62
Self-Care	.63
Ability to Travel	.32

We were able to obtain 29 sets of questionnaires with either spouse or a close other person and compared responses with patients' self-rated satisfaction. Agreements were generally close and all were significant. Table II shows that agreement as measured by Pearson Correlation Coefficients indicates strong agreement on Sexual Life, Family Relationships, Manual Dexterity, Mobility and Self-Care. Interviewer agreements as shown in Table III were significant on all items except patients' medical situation. Highest agreement between interviewer and patient were on Family Relationships (.81), Manual Dexterity and Self-Care. It is interesting that these agreements remain quite consistent whether we have only one person interviewing, or whether there are several interviewers.

TABLE IV

Comparison of Patient-Spouse and

Patient-Interviewer Correlations

Satisfaction	Spouse Correlation	Patient - Interview Correlation
Medical Situation	.42	.19 n.s.
Work	.55	.43
Sexual Life	.77	.53
Family Relationships	.70	.81
Leisure Activity	.37	.42
Social Life	.42	.48
Financial Status	.40	.35
Self-Image	.40	.52
Mobility	.67	.59
Manual Dexterity	.68	.62
Self-Care	.56	.63
Ability to Travel	.43	.32
Appetite	.47	...

Referring to Table IV, we can compare the correlation measures between spouses and close others with interviewer responses. Both agreements were highest on satisfaction with Family Relationships, but the interviewer agreed much closer with the patient than spouses. However, spouses agreed much closer with the patient on Sexual Life. Another area of large differences can be seen on Medical Situation where neither group is in close agreement with patients, and the interviewer agreements are significantly lower than spouses. The non-significant interviewer correlation indicates practically no agreement with the patient on this item. Other items show both groups to be in closer agreement with each other.

Comparing the means of the different groups shows that patients tend to rate their satisfaction higher than spouses and close others on Medical Status and Self-Image and higher than both groups on Family Relationships. Also, the patients tend to rate their satisfaction lower than the interviwer on Self-Care, Manual Dexterity and Mobility and lower than both groups on Satisfaction with Work or Homemaking Situation. Regarding Appetite, patients tended to rate their satisfaction higher than spouses or close others.

As measured by the self-rated satisfaction scale, follow up patients were significantly more satisfied with their medical situation in 1979, than they were in 1978. These patients were also significantly more satisfied with their working and financial situation in 1979, and 4 patients (31%) had experienced an improvement in their vocational status.

Although these data on follow up patients are based on a small N, the results are in the same general direction as the results for long-term vs. short-term dialysis patients, that is, relatively few differences which are statistically significant, but differences which do exist suggest an improvement over time---in turn suggesting a pattern of increasing adaptation to, and ability to successfully cope with, end stage renal disease.

In order to identify the types of psychosocial problems most severe in long-term dialysis and kidney transplant patients, we used a battery of seven self-report scales to evaluate the intellectual, emotional, and social functioning of ESRD patients. The battery is comprised of the following:

1. Revised Beta Examination (1974)
2. Zung Self-Rating Depression Scale
3. Zung Self-Rating Anxiety Scale
4. Izard Differential Emotional Scale
5. Test of Emotional Styles
6. The Family Environment Scale
7. Social Dysfunction Rating Scale

The mean I.Q. based on Revised Beta scores for the 1978 sample was 105.9 with no significant differences between long-term and short-term dialysis patients.

On emotional factors, long-term dialysis patients do not as a group manifest levels of clinical anxiety, as measured by the self-rated anxiety scale. The mean index score is 43.2 which falls at the upper end of the normal range which is 25-44. Short-term dialysis patients averaged slightly higher with a mean index score of 45.1 in their anxiety self-ratings which falls in the lower end of the symptomatic range of 45-55. There is no significant difference between the groups.

Reports of significant levels of depression and anxiety have been noted in the literature on dialysis patients. The long-term dialysis patients sampled thus far exhibit mild depression symptomology as a group. The mean Self-Rated Depression Index score is 50.5 which falls within the symptomatic range of the SDS norms which is 50-56.

Short-term dialysis patients (N=35) scored higher than long-term ($\bar{x}$=54.6, N=17, SD=11.9); however, these differences are not statistically significant.

Taken together, the results of the Zung Depression Scale and Zung Anxiety Scale indicate that both short-term and long-term dialysis patients fall near or within the symptomatic levels of anxiety and depression. If these group means and standard deviations are an accurate estimate of a normal distribution of anxiety and depression in the renal population, then approximately one-half of the population falls in the symptomatic and clinically depressed ranges of these two scales. A more accurate description of the distribution of these disorders will be possible with the additional data being collected over the next one and one-half years.

The depression and anxiety scales are designed to measure anxiety and depression as diagnostic syndromes based on the most commonly found mood behavioral and biological symptoms reported by psychiatric patients with these disorders. In contrast, the Differential Emotion Scale is designed to assess positive and negative experiential mood states or "felt emotions;" responses are not weighted by the biological and behavioral items used in the anxiety and depression scales already discussed.

Table V summarizes the results of the Differential Emotion Scale for long-term and short-term dialysis patients. The twelve emotion factors are listed in descending order of frequency and/or intensity of experience within the long-term patient group; both groups, however, are listed. Items are scored on a 1-5 scale. A score of 1 indicates that, over the past week, the emotion was "experienced" very slightly or not at all; 2, slightly; 3, moderately; 4, considerably; and 5, very strongly.

TABLE V

Average Mood State Scores of Long-Term and Short-Term Dialysis Patients

Emotion	Long-Term	Short-Term
Interest	3.7	3.3
Joy	3.4	3.1
Physical Well-Being	3.4	3.0
Fatigue	2.4	2.4
Surprise	2.0	1.7
Fear	1.9	1.9
Loss of Sexual Interest	1.8	1.7
Distress	1.7	1.9
Shyness	1.7	1.7
Guilt	1.6	1.4
Anger Outward	1.5	1.5
Anger Inward	1.4	1.5

Interestingly, long-term and short-term dialysis patients, on the average, report moderate to considerable feelings of Interest, Joy and Physical Well-Being over the previous week. On the other hand, they report very little or slight experience of Fear, Loss of Sexual Interest, Distress, Shyness, Guilt and Anger. There are no significant differences between long and short-term dialysis patients.

In contrast to the implications of the anxiety and depression inventories, then, the pattern of experienced emotions does not indicate a prevalence of dysphoric moods.

While the Differential Emotion Scale is designed to assess specific emotions and the frequency and intensity of those feelings over a fixed time period, that is the previous week, the Test of Emotional Style assesses three underlying dimensions of emotion with respect to:

(1) Responsiveness: The intensity with which a person experiences his/her feelings;

(2) Expressiveness: The degree to which the individual expresses his/her feelings outwardly; and

(3) Attitude: The degree to which the individual has a positive or negative attitude towards feeling and expressing his/her emotions.

According to Weiss an optimal score for emotional adjustment is 50% on each dimension.

The pattern of the long-term dialysis patients is one of moderation in their emotional attitude (A=43.5%), expression (E=49.4%), and response (R=48.3%). It represents a degree of stability with little evidence of conflict between the three aspects of emotion. In contrast to the moderation of the long-term patients, the pattern for short-term dialysis patients indicates considerable inhibition of the three dimensions of emotion (Attitude=31.6%, Expressiveness=38.4%, and Responsiveness=37.8%). However, this pattern also indicates little emotional conflict. Although there are apparent differences between the two groups, they are not statistically significant.

The Family Environment Scale assesses the patient's perceptions of the degree to which his family fosters interpersonal relationships, personal growth and family maintenance. These dimensions include:

(1) Cohesion - The degree that families are helpful and supportive:

(2) Expressiveness - The degree of openness about feelings;

(3) Conflict - The degree of expressed anger and general family conflict;

(4) Independence - The degree of independence fostered by the family;

(5) Achievement orientation - The degree of encouragement to achieve or compete;

(6) Intellectual-Cultural orientation;

(7) Active-recreational orientation;

(8) Moral-religious emphasis;

(9) Organization - The importance of order and organization; and

(10) Control - The extent of hierarchical organization of the family and rigidity of family rules.

Table VI shows the mean standardized scores for long-term and short-term dialysis patients. The standard score is fifty.

TABLE VI

Mean Scores on Family Environment Dimensions of

Long-Term and Short-Term Dialysis Patients

Dimension	Long-Term (N=13)	Short-Term (N=33)
1. Cohesion	53.4	53.0
2. Expressiveness	51.0	46.1
3. Conflict	37.8	37.6
4. Independence	47.8	53.0
5. Achievement Orientation	55.2	52.9
6. Intellectual-Cultural Orientation	45.2	44.8
7. Active-Recreational Orientation	37.5	37.4
8. Moral-Religious Emphasis	57.8	59.5
9. Organization	58.7	55.0
10. Control	50.8	51.2

Long-term dialysis patients perceive their families as about average in the areas of Cohesion and Expressiveness but substantially below average in Conflict. On the following Personal Growth or Personal Development dimensions, the long-term patients view their families as average: The degree of independence fostered by the family, encouragement to achieve or compete, and the degree of intellectual-cultural orientation. The families are rated substantially lower than average in active-recreational orientation and substantially higher on the degree of moral-religious emphasis.

On the family system maintenance dimensions, patients view their families as slightly higher than average in their emphasis on order and organization and average in the degree of hierarchical family organization, and rigidity of family rules.

The data reflecting the family environment are based on the patients' perceptions of the family and do not necessarily reflect congruence with the family members' perceptions. However, the ratings on some dimensions are consistent with other results. For example, the average rating for the Family Environment Scale dimension of Expressiveness is consistent with the Test of Emotional Styles ratings on the Expressiveness and Attitudinal dimensions. The low rating for family conflict is consistent with the low ratings on the dysphoric moods, especially anger, seen in the pattern of responses for the Differential Emotion Scale. There are no significant differences between long-term and short-term dialysis patients.

The Social Dysfunction Rating assesses 21 dysfunctional aspects of adjustment, especially personal satisfaction, self-fulfillment, and (to a lesser extent) social role performance. A low score indicates minimal dysfunction and a high score maximal dysfunction.

Table VII (next page) shows the mean social dysfunction scores for long-term and short-term dialysis patients. The item/factors have consensual meaning with respect to dysfunction and can be grouped into three major systems: (1) Self-System, (2) Interpersonal System, and (3) Performance System.

The results for the long-term renal patients indicate a generally minimal dysfunction pattern as perceived by the patients. This pattern is marked by the prevalence of means of 2.5 or less (rating of "very mildly" or "not at all") across the dimensions in all three major systems. The grand mean of the 21 factor means is 2.3. This simplified overall index of Social Dysfunction indicates that long-term dialysis patients perceive themselves to be "very mildly" to "mildly" dysfunctional. In other words, these patients appear to have made significant adaptation to their disease. Furthermore, it would appear that this adaptation occurs before four years post initial dialysis since there are no significant differences of any of the dimensions between long and short-term patients.

The results of the Social Dysfunction Rating Scale are essentially in agreement with the results from the Differential Emotion Scale, Test of Emotional Styles and the Family Environment Scale.

To summarize, the long-term ESRD patients in this sample generally perceive themselves as experiencing positive mood states with little incidence of dysphoric mood, have normal experience of emotions, are comfortable expressing their feelings, and have a moderately positive attitude towards both the experience and expression of feelings, and have a moderately positive attitude towards both the experience and expression of feelings in themselves and in others. They see their families as being generally supportive of relationships and personal growth with minimal family conflict and a strong emphasis on moral religious aspects of life. Overall, these patients see themselves as minimally dysfunctional with respect to their self-system, interpersonal system, and performance system. There is some concern, however, in the areas of health, feelings of hostility and suspiciousness, need for friends and social contacts, community participation, financial security and adaptive rigidity.

TABLE VII

Mean Scores on Social Dysfunction Items of Long-Term and Short-Term Dialysis Patients

Self-System	Long-Term	Short-Term
Low Self-Concept	2.2	1.8
Goallessness	1.9	2.2
Lack of Satisfying Philosophy or Meaning of Life	.9	1.4
Self-Health Concern	3.2	3.6
Interpersonal System		
Emotional Withdrawal	1.9	2.7
Hostility	2.9	2.8
Manipulation	1.4	1.6
Over-Dependence	2.5	2.1
Anxiety	2.5	2.5
Suspiciousness	2.8	2.3
Performance System		
Lack of Satisfying Relationships with Significant Persons	.9	1.0
Lack of Friends, Social Contacts	1.9	2.1
Expressed Need for More Friends, Social Contacts	3.3	3.5
Lack of Work	1.8	1.9
Lack of Satisfaction from Work	1.8	1.9
Lack of Leisure Time Activities	1.7	2.2
Expressed Need for More Leisure, Self-Enhancing and Satisfying Activities	3.1	3.0
Lack of Participation in Community Affairs	3.1	3.8
Lack of Interest in Community Affairs Which Influence Others	1.9	2.6
Financial Insecurity	3.3	2.9
Adaptive Rigidity	2.6	2.2

It should be noted that there are considerable individual differences as measured by the large standard deviations on many of the self-rating indices. This indicates a heterogeneous population, and multi-factor analyses will be required to investigate the interactions of other variables.

The information derived from this project will provide a better understanding of the nature and problems of short versus long-term ESRD patients. Such an understanding will allow better planning for assistance to and rehabilitation of these patients, as well as more efficient utilization of facilities and personnel.

In addition to the personnel who are already caring for the renal disease patient, this information will also be provided to the numerous students who participate in our education programs in the Emory University School of Medicine. The information will also be used in the training of V.R. personnel in ESRD at annual workshops sponsored by this project.

The Rehabilitation Act of 1973 identified the patient with End Stage Renal Disease as one of the groups which need greater attention and more complete services. Most psychosocial and vocational counselors have minimal experience with the patient with End Stage Renal Disease; those who do have experience lack rehabilitation-related guidelines with which to assess incoming patients or the progress of the patient. Barriers to rehabilitation have been identified in a haphazard manner, with no systematic approach. Counselors are therefore handicapped in providing for the needs of their clients. The restoration of patients to functional or vocational levels is impeded. Counselors are now required to develop an individualized written rehabilitation program for their clients but, in the case of the End Stage Renal Disease patient, often lack the data to do so.

The identification and understanding of the special problems of ESRD patients, derived from this project, will facilitate planning for expanded assistance to these patients and their families.

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Utilizing Work Potential - Vocational Assessment and Job Placement

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Technological advances in the techniques of renal dialysis have enabled thousands of Americans suffering from End Stage Renal Disease (ESRD) to survive what was once considered a terminal condition. Statistics indicate that approximately 33,000 patients are presently receiving treatment and that by 1985, it is estimated that 50,000 to 60,000 such patients will be enrolled by the Social Security Administration in the Medicare End Stage Renal Disease Program. Of this growing population, it is further estimated that approximately 40 percent might be eligible for vocational rehabilitation services.[1] From a medical standpoint, it is believed that after stabilization of the treatment process, 70 to 75 percent of those disabled by renal disease can return to their former employment or to a more compatible vocation.[2] A 1974 survey of patients on chronic dialysis suggests that only 27 percent are employed.[3] This large number of citizens who have been withdrawn from productive capacity represents not only an enormous economic drain on our society, but an extremely high cost in human terms, as well. The great need of this population for services necessary to achieve successful rehabilitation has been emphasized in the Rehabilitation Act of 1973 (Public Law 93-112, Section 2(1)) which authorizes programs for "providing vocational services to handicapped individuals... serving first those with the most severe handicaps." In defining "severe handicap," section 7(12) specifically includes renal failure among other listed disabilities.

In planning and providing rehabilitation services to the ESRD client, many factors (medical, psychological, vocational) which affect the individual's capacity to work must be considered. The ESRD client might experience such problems as reduced work tolerance (concentration and/or fatigue), physical limitations, recurring medical problems, periods of hospitalization, diet and fluid restrictions, inflexible dialysis center schedules, and time loss due to normal medical check-ups. There are multitudes of stresses which can also affect rehabilitation. Concern over the life saving procedure itself, dependency on equipment and technicians, concern over survival, financial concerns, and fmaily and societal stresses are common within this group and can produce anxiety, depression, suicide, sexual problems, uncooperativeness, and psychosis.[4]

The educational background, cognitive abilities and capabilities (i.e., I.Q., reading comprehension level, math skills, etc.), physical performance (i.e., range of motion and strength), work history, interests and motivation of the client are also of concern to the rehabilitation counselor in the planning of a program for the ESRD client.

The extent to which these factors impact on the employability of persons on hemodialysis has been the focus of research being conducted at the Job Development Laboratory, Rehabilitation Research and Training Center (RT - 9) of The George Washington University. The project staff began its work by conducting a comparative study between ESRD clients who were satisfactorily employed and those who were unemployed. This was an attempt to isolate factors which tend to inhibit or promote vocational success (project period: December 1976 to February 1978). The population for the study was composed of 22 ESRD clients who were drawn from a population of 44 potential clients undergoing hemodialysis treatment at the Dupont Circle Dialysis Center. This Center is co-sponsored by The George Washington University Medical Center which provides all medical support. Data collection was accomplished using a structured interview format designed to incorporate factors listed in the literature as having an impact on the rehabilitation process. An analysis of the compiled data revealed the following (see Table I).

Of the 22 completed client files, 9 clients were employed and 13 were not working. The employed group had a proportionally greater concentration of males to females than the unemployed group. The employed group was younger, better educated, and had a greater employment history in skilled, as opposed to unskilled, work experiences than the unemployed group. The unemployed group members were, on the average, diagnosed as having kidney disease at a later stage in their lives with onset of ESRD coming slightly sooner than onset for the employed group members. Individuals of both groups averaged approximately the same in terms of length of time in which group members had undergone dialysis treatment. However, the unemployed group reported a greater frequency of medical problems requiring hospitalization, as well as more problems with minor, secondary medical complications. This was evidenced in the much higher proportion of client refusals to be interviewed when scheduled due to minor medical problems.

In addition, as a group, the unemployed reported that they experienced high levels of fatigue for almost twice the length of time as the other group in any given week. An assessment of data measuring (client-perceived) personal and family adjustment showed a higher level of personal adjustment on the part of the working population, most important were such factors as client level fatigue, presence and frequency of secondary medical complications, lack of early vocational planning, lack of training in appropriate job skills, and financial disincentives to return to work.

Table 1

COMPARISON OF GROUP CHARACTERISTICS

Areas of Comparison		Working Group	Non-Working Group
1. Study population size		9	13
2. Age:	a) minimum	24	27
	b) maximum	51	71
	c) average	40.7	47.5
3. Sex: Female/Male		4/5	10/3
4. Education Level:	a) minimum	11	7
	b) maximum	Ph.D.	15
	c) average	12.9	11
5. Dialysis Schedule		4 day/5 evening	8 day/4 evening
6. Average Age Kidney Disease Diagnosed		32.9	43.4
7. Average Age at Onset of ESRD		39	49.2
8. Average time between diagnosis to onset of ESRD		6.1 years	5.8 years
9. Average years on dialysis		1.8	1.4
10. Average time loss due to medical problems		16 days/year	21 days/year
11. Average hours/client/ per week reported fatigue		11 hours/week	19.5 hours/week
12. Total number of refusals to be interviewed due to minor medical problems		3	11
13. Vocational experience prior to ESRD:	a) skilled	4	4
	b) unskilled	4	8
	c) none	1	1
14. Vocational experience after onset of ESRD:	a) skilled	5	0
	b) unskilled	4	0
	c) none	0	0

During the second year's activities, project staff began, developed, and implemented vocational programs for unemployed ESRD clients (project period: March 1978 to February 1979). Out of 14 clients referred, the staff assisted six clients to return to part-time employment (five working on-site and one working homebased). Vocational strategies used by the staff in an attempt to reduce vocational barriers to ESRD clients included: provision of early vocational counseling; vocational skill training; application of low cost aids to reduce fatigue experienced in performing job tasks; job restructuring; homebased employment to reduce transportation and fatigue problems; and vocational and medical follow-along services.

The results of staff activities in the second year indicate that provision of such services as listed above can result in improved vocational potential of ESRD clients. Of the six unemployed clients placed in the second year, five were able to begin work after provision of appropriate skill training, and one was placed using existing skills. In addition to skill training, two clients working in the micrographics industry were provided with equipment adaptations to increase their productivity. One client working as a camera operator was provided with a special guide to assist in proper placement of documents when being photographed. A slotted guide was added to a microfiche reader to ensure sequential viewing of microfiche cards for another client placed as a microfilm editor.

Employment barriers caused by financial disincentives were significant in preventing four of the six placed ESRD clients from considering full-time employment. Full-time employment would place these clients in an income bracket which would make them ineligible for complete medical coverage and monthly Social Security payments. The earnings they would receive would not be great enough to compensate for additional expenses they would incur.

The findings also suggest that in spite of vocational services, the occupational status (kind and hours per week of productive activity) that an individual with ESRD can be expected to achieve will have limits given various medical, psychosocial, and vocational factors. Project staff has hypothesized that medical, psychological, and vocational factors can be identified to measure the potential occupational status of the ESRD client. Testing this hypothesis comprises the focus of current research (project period: March 1979 to February 1980).

Project methodology involves: (1) identification of medical, psychological, and vocational factors significant to the vocational rehabilitation of the ESRD client; (2) development of a self-administered data collection instrument around factors identified as potentially predictive of occupational status; (3) collection of data using the developed instrument from as many ESRD clients in the Washington, D.C. metropolitan area and other geographical locations as possible; (4) identifying variables which are predictive of occupational status through computer analysis of collected data; and (5) development of an occupational status assessment tool and predictor scale based on the outcome of the data analysis. Project staff is currently involved in Step (3) of the methodology.

This project should provide rehabilitation professionals with a system for assessing the ESRD client's potential occupational status and for pinpointing problem areas so that appropriate intervention strategies can be developed. Readministering the scale at intervals to clients should also provide a means for measuring the effectiveness of intervention strategies in reducing barriers to vocational rehabilitation.

FOOTNOTES

[1]Guidelines for Development of a Model State Plan for Vocational Rehabilitation of End Stage Renal Disease Clients, Rehabilitation Services Administration, Office of Human Development: Washington, D.C., 1977.

[2]R. S. Decker, "Vocational Placement Services for the Renal Disease Client," Dialysis and Transplantation 7 (June 19, 1978).

[3]K. Lazel and S. Richman, "Physical, Mental Problems in Kidney Clients," American Rehabilitation 1(January - February 1976).

[4]N. B. Levy, "The Effect of Psychosocial Factors in the Rehabilitation of 'The Artificial Man,'" unpublished paper presented at the Symposium on Rehabilitation of the Renal Disease Patient, Emory University Regional Rehabilitation Research and Training Center, January 12, 1978.

Sexual Adjustment and End Stage Renal Disease

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My remarks today are in three parts. First, since some of you may be wondering why we are considering the topic of sexual adjustment in a vocational rehabilitation conference, I would like to point out why I think it is relevant. I believe that sexual adjustment is related to vocational rehabilitation for any group of chronically ill or disabled people, and I hope that my remarks will persuade you to agree with me.

Secondly, I am going to talk about the effects of end stage renal disease (ESRD) on sexual functioning and sexual adjustment. I hope to give you a quick, but fairly complete, review of current information about the nature of the sexual problems that these people have.

Finally, I will be talking about what vocational rehabilitation personnel and other helping professionals can do about sexual adjustment in ESRD. Granted, that most of you are probably not qualified sex therapists, is there still something that you can do to improve the functioning of these clients? I believe the answer is yes and I will be offering some suggestions on how to to that.

To begin with, let us take a look at this question of why we should be concerned at all with the sexual adjustment of these clients. Is it really necessary for a person to have a satisfactory sexual adjustment in order to work? Is there any evidence that improving a person's sexual adjustment will enhance his productivity or increase the likelihood that he might return to work? While there is not much in the way of acceptable direct scientific evidence on these points, it is certainly clear to everyone who works with these people that sexual adjustments can make a difference.

Our clients, of course, have many, very serious problems. We know from experience that sexual functioning can be especially important in the array of problems, since it bears such a direct relationship to a person's self-image and feeling of adequacy as a man or woman. Also, the development in recent years of better techniques of counseling and therapy to improve sexual adjustment means that this is one area of personal functioning that is now fairly accessible to intervention. In other words, professional help can make a difference. In addition, we know that a satisfactory sexual adjustment can be crucial to the maintenance of social and interpersonal relationships.

In a pilot study that we did at the University of Minnesota a few years ago, we invited a group of socially isolated, severely disabled people to participate in a sexual attitude reassessment seminar, followed by a series of twenty group counseling sessions which emphasized sexual adjustment. These people had been socially isolated for long periods of time, in most instances, for the duration of their disability. They were evenly divided by sex, ranging in age from the early twenties to the early forties. None were employed, married, or involved in a close relationship with another person, aside from a parent. One man had not been out of his basement apartment for over two years. During the course of counseling, four of the participants began dating within the group, two began looking for work, and all but two started to make social contacts and occasionally leave home. By the end of the series, one person announced his intention to get married and one of the job seekers found full-time employment. It appeared that dealing with sexual adjustment served as a key for these people to unlock their social withdrawal.

We are, of course, also aware of the very serious stress that ESRD places upon marriages and families. We know that the rate of marital breakdowns and abandonment by spouses is fairly high. Experience and research has also shown that vocational rehabilitation is much more likely to be successful when you have a stable and supportive family unit with which to work and, especially, when there is a spouse who can actively participate in the vocational rehabilitation process.

Obviously, anything we can do to improve sexual adjustment within the marriages or close personal relationships of these people will contribute to marital stability and to ultimate rehabilitation success.

Finally, there is ample evidence that sexual adjustment problems, by themselves, can lead to fairly pervasive problems in psychological adjustment and that such problems can impair a person's capacity for productive activity such as work. Since these clients have so many other problems, it may be that sexual adjustment, by itself, is not critical in their prospects for vocational rehabilitation. But, we do know that this is a problem for most of these clients and we know that our chances of doing something about it are excellent.

Some of these points may already be familiar to you. However, I hope that I have given you some reasons for believing that sexual adjustment is an appropriate and important topic for a conference like this.

Now I would like to turn to the nature of the sexual adjustment problems that these people have. What are the effects of ESRD on sexual functioning and sexual adjustment? Quite a few studies have been done in this area during the last few years, and the findings I will be reporting to you are drawn from the work of several researchers. Some of the details of their findings differ, but there is considerable agreement on the nature of the major problems these people face. There is also substantial agreement on the extent or frequency of these problems.

One of the most pervasive and frequent results of ESRD is a marked decrease in the frequency of sexual activity, especially sexual intercourse. For example, Abram (1) found that 45% of men showed a decrease of 50% or more in the frequency of sexual intercourse after the onset of renal disease. An additional 35% reported similar decreases after the onset of dialysis. Finkelstein (2) found that 40% reported no intercourse after starting dialysis. What this means, then, is that by the time dialysis starts for a person with ESRD, only about 20% will not have experienced a major decline in the frequency of sexual intercourse. Similar, although slightly smaller, decreases have been reported by women.

Impotence or difficulty in obtaining or maintaining an erection is another very frequent problem, reported to occur in from 56 to 70% of men in the different studies. Correspondingly, a somewhat smaller proportion of women report a "dimished capacity for arousal." Both sexes experienced a great reduction in the frequency of orgasm.

An almost universal problem is loss of sexual interest. Almost all people with ESRD experience a major decline in libido, most, if not all, of the time. Most simply say they are too tired or too sick "to do it," or to be very interested. Because of this loss of interest, the patients themselves will sometimes perceive little difficulty, but when you check with the spouse, you find a major problem in the relationship.

Incidentally, I should point out here that there is a fairly regular pattern in the onset and progression of most of these sexual dysfunctions. They tend to appear about the same time the renal disease is diagnosed, and somewhat worsen as the disease progresses (not always). They nearly always get much worse with the start of dialysis and improve somewhat with successful transplantation. However, a transplant is hardly a panacea for problems in this area, because impaired sexual functioning does not often return to the pre-dialysis level and practically never to a pre-disease level.

The reasons for these impairments are not fully understood, but it is clear that a number of factors can be, and often are, operative. Neuropathy, or degeneration of some of the nerves involved in sexual responses, is often present. Some of the drugs that ESRD patients take are known to cause impotence and/or diminished libido. Hormone changes occur and may be part of the problem for many people. It is also clear that many psychological factors are often involved and interwoven with the physical factors. Whatever specific physical and emotional influences may contribute to sexual dysfunction, it is clear that these are always overlain and greatly worsened by fatigue, general debilitation, and low energy.

All of these things go together to contribute to a serious loss of self-esteem and changes in self-image. It is difficult for a person in this condition to feel "sexy" or even personally attractive. The installation of a shunt and other physical changes necessary for dialysis, as well as the direct effects of some of the drugs used, can cause unwelcome changes in appearance. This too, sometimes contributes to major disturbances of body image and impaired sexuality.

It is clear that all of these phenomena are likely to be associated with helpful psychological complications, and these have already been discussed by previous speakers. Here, I might just remind you, though, of a couple of specific psychological problems that have particular relevance to the topic of sexual adjustment. One is depression, which occurs often enough and in sufficient severity to be recognized as a problem which may in itself require special attention. Depression certainly interferes with sexual adjustment. The other is a feeling of inadequacy in one's sexual identity. The causes of feeling inadequate as a man or woman are many and can range from the physical impairment of sexual functioning to loss of job and impairment of one's role as a spouse, mother, or father. In any case, counselors should be aware that such feelings are very common among these clients and need to be dealt with if rehabilitation efforts are to succeed.

The final negative effect of ESRD on sexual adjustment that I want to mention is loss of partner. While there is little specific information in the literature on this point, it is clear that the rates of marital breakup and loss of sexual partner are high in this group. Steele and others (3) found moderate to severe marital discord in about half of the couples they studied, and, of course, they were looking only at the marriages that had survived long enough for the partners to be studied as a couple. Much of the discord seemed to be related to the sexual dysfunction of the spouse with ESRD, but, clearly, the healthy partners and the marital relationship were subjected to quite a variety of very serious stresses. As might be expected, many of the healthy partners resolved their stress by leaving the relationship.

Needless to say, losing one's spouse or intimate friend imposes an enormous burden on the person with ESRD. It is difficult enough to maintain a relationship which may have been stable and satisfying to both partners before the onset of renal disease. However, this difficulty does not compare at all to the problems the sick person can have in finding a new partner after the onset of disease. Loss of partner or of supportive relationships, generally, can greatly complicate rehabilitation efforts, since much of the needed support and incentive for the client or patient may be gone.

Now that I seem to have completed painting a fairly bleak picture of sexual adjustment for our ESRD clients, let me turn to the positive side of the coin and talk about what we can do as rehabilitation counselors, nurses, and physicians to brighten the picture. I believe that there are some very definite, positive steps that we can take to help improve our clients' sexual adjustment and, thereby, contribute to their successful vocational, as well as psychological and social rehabilitation.

One of the first and more important things we can do is to make professionals aware of both the problems and the potential in sexual adjustment that ESRD clients have. Simply acknowledging the presence of a problem that may greatly distress a client, but which he does not feel free to bring up, can contribute much to the development of effective rapport in the counseling relationship.

Moreover, awareness of the possibilities of alleviating the problem can generate optimism and provide a focus for goal-setting in counseling that may otherwise be difficult to achieve with these clients.

I am sure you have already realized that I am not going to propose that you add sex therapy to your intervention skills. However, it is clear that a modicum of basic information and a sensitivity to problems in this area can make a big difference. Among the specific information the counselor should have is knowledge of referral resources. Most metropolitan areas that have dialysis centers also offer some access to trained sex therapists. If it appears that your patient or client needs specific therapeutic remediation of a sexual dysfunction, skilled help is usually available. However, many problems do not require therapy as such, and it may be enough for a sensitive and reasonably knowledgeable member of the rehabilitation team to take some time to talk with the client about his or her concerns and problems. This could be any member of the team--whomever the client trusts enough to talk with about such matters. At most levels of involvement, the quality of the relationship with the client is more important than the expertise of the helper.

And here, I would like to introduce you to the PLISSIT model developed by Annon (4). This indicates the levels of involvement a helping person can have in dealing with a sexual problem, and it should give you some guidance in deciding how far you should go in trying to be of help in this area.

PLISSIT is an acronym, which stands for: Permission, Limited Information, Specific Suggestions, and Intensive Therapy. At the first, and simplest level, you can often help the individual deal with a sexual problem or concern by simply giving permission for the concern to be felt and perhaps expressed. Giving permission means conveying an empathetic, concerned, but non-judgmental attitude to your client or patient concerning sexual matters. It means being sensitive and responsive to subtle or indirect expressions of sexual concerns and being enough in tune with your own attitudes and feelings about sexuality to respond appropriately and in a way that facilitates the helping process. It may even mean giving permission by taking the initiative to raise questions and thereby reassure your client that his concerns are not unusual or forbidden and that you will not be frightened or offended by hearing of them. The patient who says he "feels like Frankenstein" on the machine is more likely to be commenting on an aspect of his sexuality, than on the objective facts of the situation. It would be interesting to see where the conversation went after a response like, "I suppose at times you feel more like a machine than a real man." Here is a situation where asking a leading or loaded question may be just what is needed to give permission and possibly open up some very fruitful areas for discussion, such as his feelings of adequacy as a man, his view of his own sexuality, the quality of his sexual or other intimate relationships, etc. Because of the emotional load that sexual topics always carry in our society, people are often guilty about their sexual feelings and concerns and may be reluctant or fearful of expressing them. Permission is always a necessary first step in dealing with problems in this area.

The next level of intervention in sexual problems is that of providing Limited Information. Clients will often get hung up on their ignorance or incorrect beliefs, and moderate doses of correct information can work wonders. For example, many men are inclined to equate their masculinity with the ability to perform intercourse in the standard "missinary" position. Such men may believe that their sex life is ended when they become impotent or no longer have the strength to assume the male superior position in intercourse. In such instances, it can be of great value to learn that even the impotence of ESRD can sometimes be corrected; or, if it cannot, that sexual intercourse is usually still possible; or, if it is not possible or not desired, that other forms of sexual expression are still possible and may be very satisfying to both partners; and, even, that non-sexual intimacy may meet important emotional needs. Simply knowing these things can make a big difference in the life of a person who has been avoiding intimate relationships because of fears or misconceptions due to lack of information. Similarly, some patients may need to know that intercourse is not likely to damage their shunt or their new kidney, but they will not necessarily ask those questions. As helping professionals, we need to know that such questions are often in the minds of the people we work with; and we need to anticipate them, "hear" them when they are not spoken; and answer them with some basic, accurate information.

Incidentially, I can certainly appreciate the concern that Dr. Newman expressed yesterday that talk of sexual problems can become a self-filfilling prophecy. As one example of this, it is clear that performance anxiety, or fear of impotence, is one of the most important causes of impotence. Nevertheless, I am convinced that one of the best ways to keep problems to a minimum and to help our clients cope effectively with problems when they do arise is to fully inform them about all aspects of their condition, including the complications and their causes. To cite just one example, the onset of impotence can be fairly sudden and emotionally devastating, but the man who knows in advance that it may happen, and even that there can be some corrective meausres, is less likely than the uninformed to feel that this is a unique, or shameful, or disastrous occurrence.

Limited Information by the way, is limited to general information, which you must be careful not be particularize for the client. You should not take anything for granted about what the patient knows or believes. Your task is to make generalizations, dispel myths, eliminate stereotypes, and fill gaps in the patient's sex education. Such information can usually be conveyed without the use of any particular counseling techniques other than empathy and sensitive listening and requires only the information about sexual functioning in ESRD that most nurses, social workers, or counselors can acquire working in a dialysis program and reading a few of the main articles on the topic, such as the work of Finkelstein, Abram, Levy (5), or a few others.

If you begin to individualize any of the information you give to a client, you are going beyond the LI level to that of Specific Suggestions. The big difference here is that you have to be prepared to take responsibility for the information you provide--that is, to convey the information in a manner that insures its acceptance, and to follow up on the couple through their trials or experiments with different solutions to their problems. At this level you are suggesting specific behavior changes. Obviously, this level requires not only good counseling skills, but knowledge of techniques of sexual

therapy. It is also necessary that you have a thorough sexual history of the individual in hand before making specific suggestions, so that you have a basis for predicting or anticipating the impact of your suggestions and can be prepared in advance for any problems or adverse reactions.

You do not necessarily have to be a fully qualified sex therapist to get into the business of making specific suggestions, but you certainly must know your client well and be very familiar with all of these phenomena and problems of sexual adjustment. Also, you must realize that specific suggestions cannot be made when your involvement with the problem is limited or superficial. You must be in a position to follow up and follow through. For most of us that is really not possible, so I believe that Specific Suggestions are best left to the trained sex therapists.

The deepest level of involvement is that of Intensive Therapy, and I will not go into that because the term is pretty self-explanatory. Here, we are talking about an activity that should be carried out only by fully trained therapists, and our involvement in it should be limited to making good referrals. If you believe that your client or patient could benefit from therapeutic remediation of impotence or an amorgasmic condition, or that he or she needs to learn energy-conserving techniques of intercourse, referral to a qualified sex therapist is the most appropriate action.

The last item on my outline is "working with the family," and since that has already been thoroughly covered this morning, I will not say anything more about it. I would like to just point out, however, that in order to work with the family, we have to keep it together! Anything we can do to help our patients maintain their intimate relationships is important in this respect, because it can contribute significantly to the quality of their life and their prospects for successful rehabilitation.

I believe that if we begin to approach our patients and clients with a sensitive and empathetic ear to their concerns about their sexuality, we will be surprised at how much help can come from a little knowledge and a little special attention to this area.

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Adjustment to Transplantation - A Consumer Response

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It was around 8:00 a.m. on Thursday, June 8, 1978, when I called into the operating room. My sister was in the room next to mine where they had already started the operation to remove one of her kidneys. My wife and one of our daughters were in the recreation room of the V.A. Hospital in Nashville, Tennessee, waiting and praying. Our other daughter was at work in Atlanta, Georgia, and our son was at work in Beaumont, Texas, both waiting on the good news. An all day prayer vigil had already started at Roswell United Methodist Church in Roswell, Georgia. Other members of the family and many friends and fellow employees at AT&T were offering up prayers for my sister and me from cities throughout the country.

They had given me a spinal anethesia and a shot to relax me. Being determined to remain awake during the transplant, the shot did not put me to sleep. My body was numb from the waist down so I could not feel anything. Although I could not see the actual transplant due to a foot high screen over my upper abdomen, I could see the surgeons and hear them talking.

After a period of time, someone from the operating room next door came in with my sister's kidney. Shortly, they started the actual transplant and about two hours later I heard some cheering from members of the transplant team. My new kidney was producing urine on the operating table and someone named it, I. P. FREELY.

In my opinion, a miracle had just taken place.

At this point in time, if someone had told me that, as a result of this transplant, I would have to face far greater challenges and that the adjustments required in my life would be far greater than anything I had experienced on dialysis, I would have questioned their sanity. Just as John Newman experienced, I had adjusted to the initial shock and realization of kidney failure and had made it through the transition to acceptance. This did not occur without a greater appreciation of life and a determination to make the most of it. As a result my priorities were rearranged and I found myself involved with a new group of friends and activities that gave new meaning and purpose to my life. During the two years on dialysis, I continued to work and tried to live as normally as possible. In fact, after my initial dialysis in the hospital, I went three years without missing a day's work.

Since my adjustment to dialysis went so well, I felt that a transplant with all its advantages, would be far easier to live with. Little did I realize the potential psychological and physical problems associated with a transplant.

Actually, some of the adjustments start before the actual transplant. For example, in 1975, about four months after I started dialysis, my sister expressed a strong desire to donate one of her kidneys. This can be a very emotional experience for both families involved, and the decision was not made without considerable soul searching. We were tussue typed and since we only had a two antigen match, we were turned down for the transplant. This rejection, especially after having such high hopes, triggered a whole new set of emotional and psychological problems, not only for me, but for my sister, also, who wanted to give me a chance of a better life.

Next, I decided to have my doctor place my name in a nationwide computer bank for a cadaver kidney. Once this decision was made, I found myself faced with another type of adjustment - how to live while waiting. I know patients on the waiting list who let this possibility control their lives. They become so totally dependent on obtaining a kidney that they give up doing anything else in life. Since I felt this was no way to live, I decided to continue making the most of life while on dialysis and not worry about the future or the transplant, knowing that both were in Hands greater than mine.

About 2-1/2 years later, Nashville started using a new drug to reduce rejection. It's called A.T.S. (Anti-thoracic duct cell serium) and is infused IV following transplant for 19 treatments. It is given to destroy lymphocytes and decrease the body's ability to reject the new kidney. The Transplant Team then agreed to transplant my sister's kidney using A.T.S., since it would significantly improve our chances for a successful transplant.

For the first few days after the transplant, I was in the Intensive Care Unit where my condition was monitored very closely. Next, I was moved into a step-up unit requiring less monitoring. My kidney function continued to improve each day and by the fifth day (T + 4), my BUN and creatinine levels were almost normal. On the sixth day (T + 5), all tubes and needles were removed. What a relief this was, but then I discovered another problem. After three years of no urine output, I found myself having to go every 10 minutes. This liked to have drove me crazy and for the first few nights, I didn't get any sleep at all. At first, I blamed this on my sister's fickle female kidney. Actually, it was due to my bladder which gradually returned to normal as the muscles stretched and became stronger.

On T + 7, my sister came to visit me and she was doing great. In fact, she was released the same day, and my wife and daughter took her home. Our relationship took on a new meaning, thus requiring adjustments on the part of both.

On T + 1, I received my first A.T.S. treatment. This continued for 6 days in a row, then I skipped a day and had treatments every other day for the next 7 treatments. The last 6 were given on a one per week basis. The A.T.S. is made from rabbits, so I called these treatments my rabbit feed.

On T + 8, the renogram (an X-ray study of the transplanted kidney) showed a slight reduction in my kidney function. The Team treated it as a slight rejection and gave me a "BOMB" (a large intravenous does of a steriod drug to stop a rejection episode). The lab tests the next day showed the kidney function to be normal. The possibility of rejection is always present and this can cause all kinds of psychological problems. To live with this possibility, with piece of mind and freedom from worry, required another major adjustment and, in my case, came from a Power greater than man.

On T + 10, the renogram was good and my doctor told me the kidney was doing great and all we could do was wait. This waiting is tough because you start to imagine things, and negative thoughts, doubts, and fears tend to creep in. It is a constant battle to overcome, requiring continuous adjustments to whatever conditions occur.

For the rest of my stay in the hospital, my kidney continued to function with no more signs of rejection. On T + 20 I received A.T.S. treatment 13 and then I was released from the hospital. What a great feeling this was, and I had not dialized since the day before the transplant. I stayed with my sister in Nashville for about a week and then on T + 27, after having A.T.S. #14, I caught a plane for Atlanta. My three children met at the airport. I cannot describe how good I felt, home again.

About a week before I left the hospital, I started having some problems with some of the medication I was on. The immunosuppression drugs were rough on me from the start. Before the transplant, I was warned by my doctor in Atlanta and by the Transplant Team in Nashville about the possible side effects of the medication. At the time, the prospects of a successful transplant overshadowed these concerns.

Up to this time (18 months after the transplant) the psychological and physical problems have been far greater than what I expreienced during my three years on dialysis. Besides feeling lethargic and tired all the time, I have a tendency to become depressed. Overcoming this has been a constant battle for me.

In addition to the psychological problem, I have been hospitalized six times in the last year for the following problems:

1. Fever and stomach pains. The fever was caused by bacillus infection requiring IV antibiotics for 12 days. The stomach pains were due to gastritis, requiring medication and diet restrictions.

2. Rejection requiring 4 "Bombs" and 4 radiation treatments and increased amounts of steroids for a long period of time.

3. Hepatitis from the drugs I was taking.

4. Eye and leg problems. The eye problem was caused by Toxoplasmosis, and the leg problem was due to bilateral aseptic necrosis.

5. Toxoplasmosis

6. Toxoplasmosis

Presently, I still have Toxoplasmosis in my right eye, which is almost totally blind, and the bone problem in my hip, for which I require crutches to walk. The eye problem has been going on for over six months and is not responding to any treatment. The hip problem will eventually require surgery (total hip replacement) to correct.

In addition, I have had numerous other side effects from the drugs, such as:

1. Round face and puffy cheeks

2. Emotional change

3. Insomnia

4. Salt and water retention

5. Pimples on face and back

6. Purple and red markings on the skin

7. Mouth ulcers

8. Hair loss, which grew back curly

9. Fungus on feet, legs, and hands

10. Sores on legs

I have already missed over 140 days from work since the transplant. When I was on dialysis, I went three years without missing a single day from work. In addition, I could play golf, cut the grass, paint the house, walk and jog, and see with both eyes. Presently, I cannot do any of these things.

Several have asked me if I would make the same decision again. This is a very difficult question, and I have given it considerable thought. From a physical standpoint, I am in worse condition than at anytime while on dialysis. However, life is more than physical, and my experiences since the transplant have changed me in many ways. Most of these have made me a better person. So even though I can't give a definite yes or no to this question, I really feel the verdict is not in, but when it does come in, I will truly be able to say that the transplant was for my overall good.

In closing I would like to point out some of the things I feel were very important in my adjustment and continued employment, in spite of kidney failure. Hopefully, some of this information will be of value to you in your vocational rehabilitation activities.

SLIDE 1 FIVE CRITICAL AREAS - PATIENT REHABILITATION

Now, let me explain what I mean by these 5 CRITICAL AREAS that have greatly influenced and continue to influence my adjustment to living with a chronic illness.

SLIDE 2 CRITICAL AREA I - STATUS

What a person is, prior to kidney failure, has a tremendous influence on the type of person he will become.

For example
- An ambitious executive before, ambitious executive afterwards;
- A good housewife before, good housewife afterwards;
- Disgusted worker before, disgusted worker afterwards;
- Poor student before, poor student afterwards.

Of course, there are exceptions, and a chronic illness tends to bring out the best and worst in a person. Some do make complete changes for the better, and those of you involved in rehabilitation work should never lose sight of this potential.

The type of job a person has also has an influence on whether or not he will continue to work later. Someone with a good paying position, requiring little physical energy, is more likely to continue working than someone with a low paying, physically demanding job.

A person's marital condition has an influence on one's acceptance of a chronic illness. One who has been marrried and has grown children is more likely to accept his situation than one who is not married or who has recently married with no children or with small children.

Age is also a factor. I have observed that young children tend to have very little trouble in accepting dialysis, while teenagers and those in their early twenties have a much harder time. Some in this age group never do adjust. One young lady I knew, who had just finished high school and started a career, felt her life had ended when she started on dialysis. She viewed marriage and children as an impossible dream. After a short period on dialysis she died from heart failure, and evidence indicated it was due to a self-induced potassium overload.

Patients that are older and established in their job and family situation tend to adjust without too much difficulty.

There is no fixed rule as to how a person will adjust to ESRD, based on his status in life, but in my case I feel it had a big influence on my acceptance and adjustment.

SLIDE 3 CRITICAL AREA II - INFLUENCE

The degree of support and encouragement of others has a tremendous influence on a patient's rehabilitation. If time allowed, I could spend hours on this subject. Instead, I will give you a few personal experiences to illustrate my point.

After returning to work, following the A-V surgery and prior to starting on dialysis, I happened to be in my boss's office when the company physician called him about my medical report. My boss answered this call over his speaker-phone, not knowing what the call was about. For some reason, he continued the call this way, so I heard the entire conversation. The Medical Director asked my boss when I would be going on disability. He had automatically assumed that when I started dialysis I would no longer be able to work. If some doctors have this outlook on kidney failure, just imagine what others feel.

I will never forget how my boss answered the Medical Director's question. He replied in a loud, firm, and positive tone, "You don't know this man, because he probably won't ever go on disability." You can't imagine how good this made me feel and later, on dialysis, recalling these words helped motivate me many times.

When learning of my illness, some of my friends began to act kind of strange. I'm sure that many, not familiar with dialysis, have all sorts of ideas about the kidney machine. The other members of a golf foursome never once came to see me after I started on dialysis. In my opinion, one of the best things others can do for a kidney patient is to treat him normally. Pity from others tends to promote self-pity which is detrimental to one's rehabilitation.

I feel that many dialysis and transplant patients could do more and continue working if they were treated more normally and if those close to them encouraged them and expected more from them. It is also very important that the attending physician express a positive attitude early in the patient's treatment.

SLIDE 4 CRITICAL AREA III - OUTLOOK

One's outlook on life, in my opinion, is the most important factor in one's rehabilitation. A good attitude is over half the battle in overcoming life's obstacles and paves the way for adjustment, acceptance and what a person makes of his life in spite of his condition. On the other hand, a bad attitude can make life very difficult for all involved.

Motivation is a major factor in one's continued employment. For example, I find working for the Long Lines Department of AT&T a climate that has been very instrumental in my motivational development. At one time, when I was on dialysis, I did some research and found that of the 30,000 employees working in the Long Lines Department, there were three of us on dialysis. I got to know the other two and I learned that they, like myself, had continued to work full-time and had not even considered going on disability.

In my opinoin, one's religious convictions, or lack of them, play a major role in one's rehabilitation. In my experience with other patients, most of them seem to fit in one of the four categories:

1. They blame God for what has happened to them. This often leads to bitterness and self-pity.

2. They blame themselves for their condition. They often feel that God is punishing them for some wrong they have committed. This produces a feeling of guilt which is just as defeating as self-pity.

3. They think everything happens by chance and that God does not have anything to do with it. Some in this category are able to cope with their difficulties, while others who feel this way just give up.

4. They believe God is in control and nothing happens to us unless He allows it, and all things, no matter how bad they seem, are for our overall good.

As for me, my conviction places me in category four. Believing this way has provided the stability necessary for me to face the varying circumstances of life.

A person's outlook on life does make a difference in their rehabilitation.

SLIDE 5 CRITICAL AREA IV - RESPONSIBILITY

A patient's acceptance of responsibility for the quality of his future is critical to his rehabilitation. I feel strongly that the more a patient does for himself, the better his chance for improving the quality of his long-term future whether on dialysis or with a transplant.

While on dialysis, I assumed as much responsibility for my own care as I could, including self needle sticks. This approach kept a lot of pressure and responsibility from my wife after we were home-trained. This allowed for a much less stressful relationship during this period and improved my self confidence.

After the transplant, I continued this acceptance of responsibility for the quality of my life and future. In several instances I have detected problems and potential problems before the doctors. Sometimes I take corrective action and then notify them. I challenge and question medical personnel when I don't understand something or feel something is not right. After all, it is my life and I don't feel others have the same degree of concern for it as I do.

SLIDE 6 CRITICAL AREA V - INVOLVEMENT

This next area has been very therapeutic for me since my kidney failure. Getting involved with others with similar problems has given new meaning, purpose, and direction to my life. Some see life as through a mirror. In their trial and grief, they become morbid and self-pitying, seeing only their own sorrow, their need, their pain, the injustice of their circumstances. On the other hand, there are those who, in times of anguish and calamity, see life through a window and see the needs of others around them. Thus, with new vision, their own experience of suffering can be made a blessing. We are much better off when we look out of a window on the world, and not waste time gazing at our own personal sorrow.

There are many ways and opportunities available for anyone to get involved. Shortly after starting dialysis, the company Medical Director interviewed me on the subject of kidney disease, dialysis, and transplantation. This session was videotaped in our TV Studio and later transmitted via CCTV to all Long Lines offices in nine Southeastern states. Over 10,000 Organ Donor Cards were distributed at these locations following the CCTV program.

After about two years on dialysis, one of the company reporters came to our house and interviewed my wife and me during a dialysis session. She published a four page article in the company magazine, which has national distribution. After it was published, I received several calls about the article from different sections of the country. Almost all said how much it had helped them or someone else they gave the article to who had kidney disease.

The Kidney Foundation offers a wide variety of areas where ESRD patients can get involved in helping others with similar problems. Presently, I am on the Board of Directors, member of the Executive Committee, Vice President of the Gift of Life Committee, and a member of the Speakers Bureau.

One of the most rewarding activities I have been involved in is the Atlanta Chapter of the National Association of Patients on Hemodialysis and Transplantation (NAPHT). For the past year, I have served as the Chapter President. We have monthly meetings were patients get together and share mutual problems and solutions. We also have socials and about six educational programs a year. We have an Education Fund named in memory of Dr. Samuel Chyatte that we use to bring in noted speakers such as Dr. Friedman.

I have also participated in seminars, training courses, interviews, and other activities for medical personnel and support groups involved with ESRD patients. I have been on local TV several times, and I have given numerous talks on kidney disease and the organ donor program at clubs, churches, schools, and civic organizations.

As you can see, my kidney failure has opened up a new way of life for me. I appreciate the opportunity to share some of my experiences with you and hope that some of the things I have said will be of benefit to you in your rehabilitation work.

SLIDE 1

CRITICAL AREAS

PATIENT REHABILITATION

I. STATUS

II. INFLUENCE

III. OUTLOOK

IV. RESPONSIBILITY

V. INVOLVEMENT

SLIDE 2

CRITICAL AREA - I

STATUS

1. Job
2. Marital
3. Age

SLIDE 3

CRITICAL AREA - II

INFLUENCE

1. Family, Friends
2. Doctors, Nurses
3. Social and Rehabilitation Workers
4. Boss and Co-Workers
5. Church

SLIDE 4

CRITICAL AREA - III

OUTLOOK

1. Attitude
2. Motivation
3. Religious Convictions

SLIDE 5

CRITICAL AREA - IV

RESPONSIBILITY

Patient Acceptance

Self-Care

Quality of Future

SLIDE 6

CRITICAL AREA - V

INVOLVEMENT

Others

NAPHT

Kidney Foundation

Medical Arena

Support Group

Counseling the ESRD Patient for Vocational Planning

Elizabeth Rose, B.A.
Supervisor
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Bureau of Rehabilitative Services
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The End Stage Renal Disease client can be one of the most difficult individuals to rehabilitate. This may be due, in part, to a lack of psychological motivation on the part of the client towards his or her counselor; in part, possibly, to the heavy financial responsibilities the client may encounter during illness; and in part, to the nature of the illness itself. It is the role of the professional rehabilitation counselor to work with the client in problem areas, psychologically, vocationally, and financially, and to guide him or her towards the independence which is necessary to resume a postion in the job market.

It is important to remember that the VR Counselor is a member of a professional team which also has as its goal, the return of these individuals to productive life. At the time of referral, the VR Counselor is already working as a part of the team by discussing the physical and social problems that the potential client is encountering.

At the time that the client comes in for the initial interview, the counselor should have already made use of these resources which are available in the dialysis unit. He or she should know the client's general medical history, the treatment plan, and the prognosis. He should also have obtained pertinent family and social information from the unit social worker and other personnel. If the client is already on dialysis, the VR Counselor should have some idea of how he is adjusting to the changes in his life which have been brought about as a result of his illness. The counselor must make use of information gleaned from these sources to help determine the client's eligibility for services.

The initial interview itself should be scheduled in the counselor's office, if at all possible, rather than taking place on the unti while the client is undergoing dialysis. This is a first step in indicating to the client that he is not an invalid and must take some responsibility to help himself. It also gives the counselor and client the privacy which is necessary in order to have a meaningful session. The counselor should begin at this point to have the client become accustomed to seeing him as a vocational rehabilitation counselor. Even though the VR Counselor is a part of a team and will continue to be, it's good for the client to realize who and what the counselor is and precisely what VR is providing. It's also important to remember that this interview is probably the first contact that the client will have had with VR. To the client, the counselor is VR. The manner in which this initial interview is handled can affect the rest of the entire rehabilitation program.

The counselor should begin, here, to emphasize that the rehabilitation is a positive one. This attitude must be carried all the way through the rehabilitation process in the counselor's attempts to place the emphasis on the client's strong points, rather than on his weaknesses.

During this time, the counselor must emphasize the positive aspects of the client's total life. The counselor must assure the client that he is aware of many of the physical and psychological stresses that he is undergoing and that, by working together along with the other professional team members, many of these problems can be overcome.

The counselor should get pertinent data from the client at this time and should obtain a statement of the client's problem as he sees it. The client should leave the interview with the feeling that he and his counselor are going to work together to come up with a satisfactory solution to his problem.

If handled correctly, the initial interview will have set the stage for continued counseling with the client. Within the next 2-3 sessions, the counselor should be securing additional information and should be working with the client towards developing his IWRP. It's at this point that the counselor, having learned from discussions with the client, from medical information, and other sources, the clients functional limitations, really begins to do vocational counseling.

He must keep in mind the individual client's treatment plan. This is due to the fact that the vocational future of the client is greatly affected by whether his is a transplant candidate or whether he will remain on permanent dialysis.

The client, who for physical reasons or through personal choice, remains on dialysis has a difficult time in returning to work. He has, at times, many actual or threatened losses. He may encounter weakness, restricted use of upper extremities, peripheral neuropathy, severe depression, dependency, and numerous other disappointments. All of these factors must be dealt with honestly and realistically by the client, as well as the counselor, in order that a complete rehabilitation can be achieved. The unpredictability of just feeling well represents a unique stress for ESRD clients, compared to stresses facing clients with other chronic diseases such as multiple sclerosis, diabetes mellitus, or arthritis. The "feeling good" may be frustrated by dietary restrictions, and others. To the client, life itself is unpredictable. The kinds of psychological stresses faced by kidney patients are closely related to the concept of self image and are related to such things as efficiency on the job, economic status, aspiration for the future, and physical appearance and attractiveness. Being on dialysis 2-3 times per week eliminates many job choices for the client.

The counselor needs to assist the dialysis patient in seeing himself as a functioning individual who still retains some control over his life. A key

items to remember is that all counseling, diagnostic services, physical restoration, or training must be geared to rehabilitating the client to employment that is compatible with the functional limitations imposed upon him by his disability.

It is usually much easier to establish a vocational goal with a client who will be transplanted. This is simply due to the fact that if the transplant is successful, he has very few occupational barriers to contend with as far as physical limitations are concerned. However, the counselor must keep in mind the lack of knowledge by employers and the general public as to the realities of life with a transplanted kidney. Part of the counselor's role is to help educate the potential employer.

There is also, usually, a time frame within which to work for those people who are due to have a live, related transplant, as opposed to a cadaver. As part of the team, the VR Counselor is kept informed as to potential donors, and the date the transplant is to take place. During the time period between onset of dialysis and the date of transplant, the counselor should be working with the client on a continuing basis. He should be helping the client to develop or to reshape vocational goals. There are decisions to be made with the client. Should he enter a training program now? Should he wait until after his transplant? These are decisions which have to be made on an individual basis. Each client has a different physical and emotional reaction to his illness and to his treatment.

Vocational planning is more difficult with a client who is awaiting a cadaver transplant. There is no set time frame within which to work. There is also the accompanying psychological stress imposed upon the client. He sometimes finds it difficult to think of anything except the possibility of transplant. This is also true of those clients awaiting a live, related transplant. Since it can be two to three years before a matching cadaver kidney becomes available for the client, it is important to make sure that continuous counseling and guidance are taking place during this period in his rehabilitation program. The counselor should constantly be working in conjunction with the rest of the team members. Because many other things such a marital difficulities, the physical side affects of ESRD, etc., can influence the client's receptiveness to vocational planning, the counselor needs to be aware of them and be able to work with the rest of the team to help the client to overcome them.

There are problems that need to be dealt with after transplant as well. If the transplant is considered successful, the client sometimes goes through a euphoric state. The euphoria sometimes influences him to come up with a vocational goal that is totally different than that planned for on his IWRP and may be totally unrealistic. The counselor should be able to talk with him and, knowing him well, should be able to help him see whether he is capable of reaching the new goal that he has set for himself. Again the VR Counselor should make use of all available resources to help the client decide on a definite, realistic goal. Such tools as psychological reports, vocational evaluations, work evaluations, etc. should be used.

The counselor should also be prepared to deal with the emotional and physical results of an unsuccessful transplant. There will be re-shaping, perhaps, of vocational goals. There will be counseling needed to assist the client in adjusting to resuming dialysis. He is once again dependent on the dialysis machine and is again confronted with those problems which accompany it.

During all stages of the rehabilitation process, the VR Counselor must be aware of the financial disincentives for resuming employment. They must be dealt with realistically. It is the client's choice as to whether returning to gainful employment will enable him to have an income comparable to that which he currently may have as a result of Medicaid or Social Security. The counselor is also instrumental in securing these financial resources for the client while he is undergoing dialysis and related treatment.

In general, the VR Counselor attempts to foster independence. He facilitates decisions and decision making by making available to the client information which he can use subsequently, to make his or her own decisions. Good vocational counseling mandates that the counselor offer the client alternatives to his or her former situation. The counselor attempts to motivate the client towards returning to employment. In many instances, the client's former job is no longer available or his illness will not permit him to resume that type of work. The counselor then works with the client and helps him choose a vocation that is suitable to educational and performance levels, and one that is compatible with the disability.

The rehabilitation counselor not only provides counseling, but is unique in that he can provide the direct and immediate services that the client needs for his rehabilitation. He is able, by integrating social, medical, and financial information, to determine with the client what these services are and how best to provide them. All counselors, regardless of work setting, can coordinate services with other agencies, using them as primary resources, when their use is timely and adequate.

In summary, the VR Counselor is a coordinator of services, financially, vocationally, and psychologically. All of the services are directed toward the client to help lead him through a rehabilitation process which will enable him to become an independent, functioning member of society. There are no routine cases for a counselor and the purpose is one of awesome responsibility to facilitate developmental possibilities and give meaning and purpose to the whole process of physical and vocational rehabilitation.

"Vocational Rehabilitation and End Stage Renal Disease"
December 11, 12, & 13, 1979
Denver, Colorado

PROGRAM EVALUATION

What is your specialty?_____

DIRECTIONS: We would appreciate your responses to the following statements by your checking the appropriate spaces. Also, please feel free to comment on any aspect of the program in the spaces provided at the bottom.
Please answer every question.

Strongly Agree	Agree	No Opinion/ Not Applicable	Disagree	Strongly Disagree		
33%	59%	____	8%	____	1.	In my opinion, the objectives of this program were clearly stated.
66%	33%	____	1%	____	2.	Generally, I found the speaker(s) were well informed on the topic(s).
30%	58%	____	12%	____	3.	I thought the speaker(s) were well aware of the listener's level of knowledge and frame of reference.
25%	74%	____	1%	____	4.	Generally, I felt the speaker(s) communicated the message(s) in an effective manner.
37%	55%	6%	2%	____	5.	I felt the message(s) by the speaker(s) relevant to the program objectives
30%	48%	11%	11%	____	6.	The descriptive information received was an accurate representation of the program.
37%	63%	____	____	____	7.	The use of visual aids (charts, graphs, demonstrations, etc.) was adequate.
26%	70%	2%	2%	____	8.	The program facilities (meeting rooms, auditorium, etc.) for this program were well selected.

SPECIALITIES:
Social workers - 3
VR Counselors - 22
Public Admin. - 1
RN - 6
Ex. Director - 1
Research - 1
Supervisor - 1

Appendix A

Workshop Faculty
"Vocational Rehabilitation and End Stage Renal Disease"
December 11 - 13, 1979
Denver, Colorado

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Appendix B

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"Vocational Rehabilitation and End Stage Renal Disease"
December 11 - 13, 1979
Denver, Colorado

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